

1986

Quality-of-Life Ethics and Constitutional Jurisprudence: The Demise of Natural Protection for the Disabled and Incompetent

Robert A. Destro

The Catholic University of America, Columbus School of Law

Follow this and additional works at: <https://scholarship.law.edu/jchlp>



Part of the [Health Law and Policy Commons](#)

Recommended Citation

Robert A. Destro, *Quality-of-Life Ethics and Constitutional Jurisprudence: The Demise of Natural Protection for the Disabled and Incompetent*, 2 J. Contemp. Health L. & Pol'y 81 (1986).

Available at: <https://scholarship.law.edu/jchlp/vol2/iss1/9>

This Article is brought to you for free and open access by CUA Law Scholarship Repository. It has been accepted for inclusion in Journal of Contemporary Health Law & Policy (1985-2015) by an authorized editor of CUA Law Scholarship Repository. For more information, please contact edinger@law.edu.

QUALITY-OF-LIFE ETHICS AND CONSTITUTIONAL JURISPRUDENCE: THE DEMISE OF NATURAL RIGHTS AND EQUAL PROTECTION FOR THE DISABLED AND INCOMPETENT

*Robert A. Destro**

Much like the current debate over other related civil rights areas such as affirmative action¹, religious freedom², and discrimination on the basis of age³ or handicap⁴, the legal debate over the rights of the disabled and sick to basic medical care, food and water has largely taken place at a rhetorical and pragmatic level rather than one of substance. To be sure, the central ethical and legal dilemmas have sometimes been discussed in the cases⁵, but the courts have largely avoided both meaningful discussion of the implications of the "value of life" ethic which drives their holdings, and the effect that the common-law judicial preference for "case by case" analysis⁶ will have on the direction of the law over the long term. It is as if the core ethical issues — those which relate to the "value" of the life at stake — have been resolved by a tacit agreement to disagree on the ultimate question: whether the law has the right to base the protection it affords upon a subjective evaluation of the "quality" of an individual's life. The debate can then take place on a level where the highest value appears to be reaching some agreement on a policy which appears to accommodate conflicting ideals and values involved.⁷ Thus the focus in the "hard cases" now reaching the courts is generally on *who*

* B.A. 1972, Miami University, J.D. 1975, University of California, Berkeley. Assistant Professor of Law, Columbus School of Law, The Catholic University of America; Member, United States Commission on Civil Rights.

1. See *infra* notes 10, 13, 68, 77, 85, 91, 242 and accompanying text.

2. See *infra* notes 97, 114, 210, 242 and accompanying text.

3. See *infra* notes 18-23 and accompanying text.

4. See *infra* notes 24-71 accompanying text.

5. See, e.g., *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985).

6. See *id.* 98 N.J. at 387-88, 486 A.2d at 1244.

7. See, e.g., *Roe v. Wade*, 410 U.S. 113, 150, 159 (1973); *Doe v. Bolton*, 410 U.S. 179 (1973). See also Destro, *Abortion and the Constitution: The Need for A Life-Protective Amendment*, 63 CALIF. L. REV. 1250, 1252-61 (1975) [hereinafter cited as *The Need for Life-Protective Amendment*].

shall make the decision, rather than what decisions they should make; or on the most effective method by which to resolve the difficult medico-legal problems now facing the courts, rather than on the core "value of life" issues presented by the cases themselves.

When "value of life" issues are discussed, it is often in a religious context. This, in turn, all too often gives rise to the complaint that to resolve the core issues themselves is to attempt to impose a certain social morality on those who would prefer that the law adopt a different moral perspective.⁸

Unfortunately, such attempts to avoid the inevitable do not work in the life of the law; for the march of *stare decisis*⁹ is inexorable. Today's implicit assumptions drive tomorrow's decisions on the same or similar topics, and the law rapidly reaches issues which, only a few years before, would have been considered unthinkable for judicial resolution¹⁰. In the pages which follow, I will try to draw a few parallels between the debate over some of the

8. Such arguments generally rest on a broad understanding of the values of "privacy" and "self-determination", and see ethical or moral argument which does not further these values as attempts by others to impose their own ethics on those who do not share them. See generally *Roe v. Wade*, 410 U.S. 113 (1973); *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983); PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH, DECIDING TO FOREGO LIFE SUSTAINING TREATMENT (1983) [hereinafter cited as DECIDING TO FOREGO LIFE SUSTAINING TREATMENT]. See also W.F. Buckley, "Firing Line," Public Broadcasting Service, January 5, 1986 (debate between Rev. Robert Barry and Ms. Alice Mehling, Executive Director of the Society for the Right to Die).

9. *Stare decisis* (literally, "the matter has been decided") is the term used to describe the reliance of common law courts on the weight of precedent.

10. Compare, e.g., *Roe v. Wade*, 410 U.S. 113, 165 n.67 (1973) (stating that the decision had nothing to do with the rights of the father or any other person); *Doe v. Bolton*, 410 U.S. 179 (1973) (lack of maternal health rationale invalidates abortion regulations which limited access to the procedure) and *Regents of the Univ. of Cal. v. Bakke*, 438 U.S. 265 (1978) (use of race as a criterion for admission to a university is permissible when race is only one of many factors considered) with *Planned Parenthood of Cent. Miss. v. Danforth*, 428 U.S. 52 (1976) (father has no right to consent); *City of Akron v. Akron Center for Reproductive Health*, 462 U.S. 416, 427 n.10, 439-41 nn.29-31, 446-49, 468-71 & n.12 (1983) (majority opinion per Powell, J. and dissent per O'Connor, J.) (municipal regulation of abortion procedures designed to protect maternal health struck *in toto* because Court felt that they burdened right to abortion; abortions may be performed on immature minors without parental notice or consent upon the order of a court notwithstanding provisions of Ohio Juvenile Code and court rules requiring, on constitutional grounds, that parents be notified of any proceeding involving the interests of their children) and *United Steelworkers v. Weber*, 443 U.S. 193 (1979) (private plans giving preference on the basis of race are permissible under Title VII of the Civil Rights Act of 1964, 42 U.S.C. §§ 2000e-2(a),(d)(1982), even though it forbids racial discrimination in private employment). But see *Firefighters Local Union No. 1784 v. Stotts*, 467 U.S. 561 (1984) (race discrimination in layoffs prohibited by Title VII); *DeFunis v. Odegaard*, 416 U.S. 312, 320, 331-44 (1974) (Douglas, J., dissenting on the grounds that all forms of discrimination on the basis of race are illegal, regardless of the race of the victim). The "incremental" development of the law from its basic assumptions is discussed *infra* text accompanying notes 78-96, 241-44.

major civil rights issues of the day and the developing law and ethics dealing with the rights of handicapped newborns,¹¹ the helpless and dying.

Part I of this article will attempt to identify some of the basic legal issues in the debate over the rights of the disabled and aged to minimal health care and nourishment. Part II will argue that the practice of defining the rights of the person functionally, rather than as a matter of principle, is an old one which had largely been eliminated after the adoption of the Fourteenth Amendment, but that it is now resurgent in some quarters as a means to an end which would be impossible were the definition to be based on an explicit principle of equality. In the context of bioethics, this debate has come to be known as the dispute between the "sanctity-of-life" ethic and the "quality-of-life" ethic, and Part II will examine its importance in the context of constitutional law. Part III will argue that the process of case-by-case analysis is, by its nature, a slope, and that without the anchor of a clear agreement over ethical principles governing the equality of human persons, the law will progress in linear fashion to the ultimate realization of the principles upon which it is based. It will contend that ambiguity in the law governing courts and surrogates creates an unfettered discretion which is inconsistent with basic constitutional protections, and that *stare decisis* will hamper thoughtful

11. Too often commentators do not distinguish between cases involving children born with a malformation or congenital defect which is correctable or treatable (handicapped newborns) and children who are simply born too early (premature babies) or whose conditions are ultimately incompatible with life and where treatment will simply prolong the process of dying. The decisionmaking process for the latter involves a determination to withdraw treatment because further treatment would be futile and the child is in the process of dying. Such a decision is based purely on medical factors. In the case of a handicapped newborn, however, the decision-making process is often based, not on medical criteria, but on quality-of-life factors. Where treatment is withheld because the child will continue to live with a disability, then the decision is based on discriminatory attitudes toward those with disabilities. Where the decision is based on sound medical judgment that the treatment is futile, the decision cannot be described as one raising civil rights concerns.

The distinction is important. If the two types of cases are considered to be conceptually identical, then it becomes easy to describe the decision-making process as identical as well, even though some decisions can be said to be based on valid medical criteria and others on illegal discriminatory attitudes. See *Hearings on the Protection of Handicapped Newborns*, United States Commission on Civil Rights, at 4-5, 22-26 (June 12-14, 1985) (testimony by C. Everett Koop, M.D., Surgeon General, U.S. Public Health Service; David McLone, M.D., Chairman, Division of Pediatric Neurosurgery, Children's Memorial Hospital, Chicago, Illinois; and Mildred T. Stahlman, M.D., Director, Division of Neonatology, Vanderbilt University). See also *In re Infant Doe*, No. GU8204-00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *aff'd sub nom.*, State of Indiana on Relation of Infant Doe by Guardian, No. 482 S139 (Ind. S. Ct. May 27, 1982), No. 482 S.140 (Ind. S. Ct. Apr. 26, 1983), *cert. denied*, 464 U.S. 961 (1983).

The analytical distinction set for the above is well-settled in American employment discrimination law. See generally B. SCHLEI & P. GROSSMAN, *EMPLOYMENT DISCRIMINATION LAW* 1195-96 (1976).

attempts to force reconsideration of prior decisions which are alleged to be erroneous and subversive of the rights of individuals.¹² The article will conclude by rejecting both the functional definition of the human person, and the primary role of courts (and of the ethicists upon which they rely for assistance) in what I consider to be the case-by-case erosion of fundamental human rights principles.¹³

I. GETTING BACK TO BASICS: THE LEGAL RIGHTS OF THE DISABLED, TERMINALLY ILL, AND AGING

The best place to begin the discussion of the rights of the disabled, ill or elderly in this country is with the fourteenth amendment to the Constitution of the United States; for it figures prominently in virtually every aspect of the discussions which follow. It provides:

All persons born or naturalized in the United States, and subject to the jurisdiction thereof, are citizens of the United States and of the State wherein they reside. No State shall make or enforce any law which shall abridge the privileges or immunities of citizens of the United States; nor shall any State deprive any person of life, liberty, or property, without due process of law, nor deny to any person within its jurisdiction the equal protection of the laws.¹⁴

The present discussion begins with the Equal Protection Clause. It provides

12. Cf. *City of Akron v. Akron Center for Reproductive Health*, 462 U.S. 416, 419 n.1 (1983) (opinion of the Court per Powell, J., discussing the role of *stare decisis* in constitutional law in the face of an argument that the Court's approach to the issue was wrong as a matter of constitutional law).

13. See *infra* notes 121-98, 241-44 and accompanying text. A key consideration, of course, is the identity of the governing human rights principle at issue. The courts have only recently begun to address the issue in the context of bioethics, see *infra* Part II but have been wrestling with the same type of issue in the ongoing debate over the equality principles which are the foundation of the nation's civil rights laws. See, e.g., *Firefighters Local Union No. 1784 v. Stotts*, 467 U.S. 561 (1984); *United Steelworkers of America v. Weber*, 443 U.S. 193 (1979); *Regents of the Univ. of Cal. v. Bakke*, 438 U.S. 265 (1978); *Korematsu v. United States*, 323 U.S. 214 (1944); *Plessy v. Ferguson*, 163 U.S. 537 (1896). See also *infra* notes 122-32.

At issue in all three cases were federal statutes which explicitly forbade discrimination on the basis of race, and in all three strong policy arguments were made that justice required a reading of the statute other than in accordance with its literal meaning. In *Stotts* and *Weber* the issue was whether Title VII of the Civil Rights Act of 1964 forbids all racial preferences in employment — as the language provides — or only those which are *not* designed to increase minority participation in the workplace: i.e., discrimination aimed at minorities which suffer "invidious" discrimination. Compare 42 U.S.C. §§ 2000e-2(a),(d) (1982) (making it unlawful to "discriminate . . . because of . . . race" in hiring, promotion or job training) with *Bakke*, 438 U.S. at 324, 357-62 (opinion of Brennan, White, Marshall & Blackmun, JJ.). In *Bakke*, the issue was whether Title VI of the Civil Rights Act of 1964, 42 U.S.C. § 2000d, and the fourteenth amendment forbid the use of race in university admissions.

14. U.S. CONST. amend. XIV, § 1.

that "[n]o State shall . . . deny to any person within its jurisdiction the equal protection of the laws."¹⁵ The construction given the clause by the United States Supreme Court is rather involved, and the short excursus into the complexities of its construction which is necessary to an understanding of the legal arguments which follow has been relegated to the footnotes.¹⁶ For

15. By its terms, the clause applies only to the several States, but the Supreme Court has construed the Due Process Clause of the fifth amendment, U.S. CONST. amend. V, as including "an equal protection component". See, e.g., *Weinberger v. Wiesenfeld*, 420 U.S. 636, 638 n.2 (1975); *Schlesinger v. Ballard*, 419 U.S. 498, 500 n.3 (1975); *Bolling v. Sharpe*, 347 U.S. 497 (1954). See generally Karst, *The Fifth Amendment's Guarantee of Equal Protection*, 55 N.C.L. REV. 541 (1977); J. NOWAK, R. ROTUNDA & J. YOUNG, *HANDBOOK ON CONSTITUTIONAL LAW* 516-19 (1978).

16. There are several levels of judicial scrutiny which can be brought to bear on a legal classification which has been challenged on grounds that it violates the Equal Protection Clause. Currently known as "two-tiered" analysis, the level of scrutiny depends upon the interests at stake and the degree to which they are protected by the constitution or cases decided by the Supreme Court.

The first, and most lenient, is sometimes referred to as the "any reasonable basis" standard and appears in *Lindsley v. Natural Carbonic Gas Co.*, 220 U.S. 61 (1911). It provides that the legal classification in question will be upheld if "any state of facts reasonably can be conceived that would sustain it . . . [and that o]ne who assails the classification . . . must carry the burden of showing that it does not rest upon any reasonable basis, but is essentially arbitrary." *Id.* at 78-79. A slightly more rigorous version of this standard appears to suggest a more active judicial role. It appears in *Royster Guano Co. v. Virginia*, 253 U.S. 412 (1920). It provides that "the classification must be reasonable, not arbitrary, and must rest upon some ground of difference having a fair and substantial relation to the object to the legislation, so that all persons similarly circumstanced shall be treated alike." *Id.* at 415. See generally W. LOCKHART, Y. KAMISAR & J. CHOPER, *THE AMERICAN CONSTITUTION* (5th ed. 1981). Beyond these basic standards are the second-tier, or "higher" levels of judicial scrutiny which are reserved for legal classifications which involve "suspect" or "quasi-suspect" classes of individuals. The "suspect" category, which includes race and national origin, is the highest level of judicial scrutiny and results in almost certain invalidation of the challenged classification. See, e.g., *Palmore v. Sidoti*, 104 S. Ct. 1879 (1984); *DeFunis v. Odegaard*, 416 U.S. 312 (1974) (Douglas, J., dissenting); *Hunter v. Erickson*, 393 U.S. 385 (1969); *Brown v. Board of Education*, 347 U.S. 483 (1954); *Plessy v. Ferguson*, 163 U.S. 537, 552 (1896) (Harlan, J., dissenting), but cf. *United Steelworkers v. Weber*, 443 U.S. 193 (1979); *Regents of the Univ. of Cal. v. Bakke*, 438 U.S. 265 (1978); *Fullilove v. Klutznick*, 448 U.S. 448 (1980). The "quasi-suspect" classifications, alienage and illegitimacy, raise rather complex questions concerning the asserted justification for the classification, and the burden of proving the need for the classification is on the state. See, e.g., *Bernal v. Fainter*, 104 S. Ct. 2312 (1984) (alienage); *Mills v. Habluetzel*, 456 U.S. 91 (1982) (illegitimacy); *Cabell v. Chavez-Salido*, 454 U.S. 432 (1982) (alienage); *Lalli v. Lalli*, 439 U.S. 259 (1978) (illegitimacy).

In recent years the Court appears to have developed a "middle tier" scrutiny which is applied to legislative classifications based on sex. This standard focuses on whether the gender-based classification is substantially related to an important governmental objective. See, e.g., *Mississippi Univ. for Women v. Hogan*, 458 U.S. 718 (1982); *Rostker v. Goldberg*, 453 U.S. 57 (1981); *Michael M. v. Superior Court*, 450 U.S. 464 (1981); *Craig v. Boren*, 429 U.S. 190 (1976). Whether this is a new "level", or merely a reformulation of the slightly more rigorous *Royster* test is beyond the scope of this essay.

These "standards" are worthy of mention in this section because the Court's recent terms

present purposes, the discussion of relevant equal protection standards will focus on two potential types of discrimination: age and handicap,¹⁷ or disability.

Discrimination on the Basis of Age

Discrimination on the basis of age is a relatively new and undeveloped concept in American law. Beginning with the Older Americans Act in

have seen an extension of its willingness to invalidate legislative classifications if they reflect "irrational prejudice" or tend to perpetuate a stereotyped "archaic or overbroad" view of the individuals affected by the classification. See *City of Cleburne, Texas v. Cleburne Living Center, Inc.* 473 U.S. —, 105 S. Ct. 3249 (1985); *Mississippi Univ. for Women v. Hogan*, 458 U.S. 718 (1982). The *Cleburne* case, for example, involved exclusionary zoning of the mentally retarded, and indicates that a majority of the Court is willing to scrutinize the factors which seem to motivate the classification, even though some "rational basis" might be found for it. Notably, however, it has refused to extend the "quasi-suspect" or "suspect" labels to cases involving either age or mental disability, and appears to prefer a case-by-case approach to the particular justifications raised, rather than a "blanket" assumption that the classification is defective unless related to some important governmental objective. Compare *Cleburne*, 473 U.S. —, 105 S. Ct. at 3257-58 (1985) (retardation) ("[I]f the large and amorphous class of the mentally retarded were deemed quasi-suspect . . . it would be difficult to find a principled way to distinguish a variety of other groups who have perhaps immutable disabilities setting them off from others, who cannot themselves mandate the desired legislative responses, and who can claim some degree of prejudice from at least part of the public at large. One need mention in this respect only the aging, the disabled, the mentally ill, and the infirm. We are reluctant to set out on that course, and we decline to do so.") and *Massachusetts Bd. of Retirement v. Murgia*, 427 U.S. 307 (1976) (age) with, e.g., *Mississippi University for Women v. Hogan*, 458 U.S. 718, 735 (1982) (majority opinion of O'Connor, J., applying the standard developed for gender cases and looking at traditional prejudice as one factor; and dissenting opinion of Powell & Rehnquist, JJ., arguing that the standard should only be applied to those cases where the classification is alleged to harm members of the class alleged to be adversely affected by the classification). It should be noted, however, that discrimination on the basis of age and handicap are prohibited by statute under certain circumstances. See *infra* notes 18-20. Since either condition may play a role in medical treatment decisions, the use of either condition as a rationale for withholding otherwise available medical treatment should raise a number of important constitutional as well as statutory questions. This point is discussed in greater detail in the text accompanying notes 24-62.

For an extensive discussion of the concept of equal protection and its application to specific types of classifications, see generally J. NOWAK, R. ROTUNDA & J. YOUNG, *HANDBOOK ON CONSTITUTIONAL LAW* 516-687 (1978). Tussman & TenBroek, *The Equal Protection of the Laws*, 37 CALIF. L. REV. 341 (1949).

17. Although the term "disability" is to be preferred on the basis of its greater descriptive accuracy, the term "handicap" is also used in this context because it is the terminology of the statutes governing the rights of the disabled. See, e.g., Exec. Order No. 11,478, 34 Fed. Reg. 12,985 (1969) (prohibiting employment discrimination by the federal government on the basis of, among other things, "handicap"); Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1982) (prohibiting discrimination against "otherwise qualified handicapped individual[s] . . . solely by reason of handicap, . . ."); 42 U.S.C. § 1975c (a)(1) (1982) (conferring jurisdiction on the United States Commission on Civil Rights to investigate discrimination on the basis of, among other things, "handicap"); The Education for All Handicapped Children Act of 1975, 20 U.S.C. § 1400 (1982).

1965¹⁸ and continuing with the enactment of the Age Discrimination in Employment Act,¹⁹ the United States Congress has expressed a clear concern that the elderly be accorded both the attention required by their special needs and equality of treatment in the workplace.²⁰ To date 45 states and the District of Columbia have followed suit and have prohibited discrimination on the basis of age in employment and other fields.²¹ At the constitutional level, age has not been made a "suspect" classification under the Equal Protection Clause, but members of the Court have indicated that age-related legal disabilities would be looked at with somewhat greater scrutiny than other types of classifications.²² For purposes of this essay, however, it would not be entirely accurate to discuss discrimination on the basis of age as a separate category; for most of the problems which will be discussed are not solely a function of age. Rather, they are "mixed" questions, involving those whose illnesses or disabilities leave them vulnerable to discrimination. It is at this point that the age of the individual can and has become a factor in decisions not to provide food, water or other basic medical care.²³ Thus, where discrimination is on the basis of age-related disability, the topic will be discussed under the standards appropriate to disability generally.

Discrimination on the Basis of Disability

By contrast with the law governing discrimination on the basis of age, the law governing discrimination on the basis of handicap or disability is developing at an increasing pace.²⁴ Federal law requires that any federally funded

18. Older Americans Act of 1965, 42 U.S.C. § 3001 (1982).

19. 29 U.S.C. § 621 (1982).

20. See generally H. EGLIT, *AGE DISCRIMINATION* (1984).

21. See, e.g., ALASKA STAT. §§ 18.80.200, *et seq.* (1981); CAL. GOV'T CODE §§ 12940, *et seq.* (West 1980 & Supp. 1984); D.C. CODE ANN. §§ 1-2512, *et seq.* (1981 & Supp. 1983); FLA. STAT. ANN. § 760.01 (West Supp. 1984), §§ 112.043-.044 (West 1982); OHIO REV. CODE ANN. § 4101.17 (Page 1980), §§ 4112.01, *et seq.* (Page 1980 and Supp. 1983); WIS. STAT. ANN. §§ 111.31, *et seq.* (West 1974 & Supp. 1983-84). It should also be noted that age discrimination does not affect only the elderly; the young, especially children, may be victims of discriminatory treatment as well. See, e.g., *Marina Point, Ltd. v. Wolfson*, 30 Cal. 2d 721, 640 P.2d 115, 180 Cal. Rptr. 496 (1982); *Adrian Mobile Home Park v. City of Adrian*, 94 Mich. App. 194, 288 N.W.2d 402 (1979). See generally Travialo, *Suffer the Little Children—But Not in My Neighborhood: A Constitutional View of Age-Restrictive Housing*, 40 OHIO ST. L.J. 295 (1979).

22. *Massachusetts Bd. of Retirement v. Murgia*, 427 U.S. 307, 317 (1976) (Marshall, J., dissenting).

23. See, e.g., *In re Dinnerstein*, 6 Mass. App. Ct. 466, 380 N.E.2d 134 (1978); *In re Heir*, 18 Mass. App. Ct. 200, 644 N.E.2d 959 (1984). It is necessary to distinguish between cases which involve the very young — i.e. the extremely premature newborn where the attempt is not so much to treat as it is to bring to a level of physical maturity which will enable the individual to survive on his own—and those which involve disabilities. See *supra* note 11.

24. See, e.g., *Cleburne*, 473 U.S. —, 105 S. Ct. 3249 (1985) (constitutional standard for

program or activity must refrain from discriminating against an "otherwise handicapped" individual "solely on the basis of his handicap,"²⁵ and many state and local laws provide similar protection.²⁶ The present analysis therefore will begin with an examination of basic federal standards governing discrimination against the handicapped generally, and relate them to the question of discrimination against the disabled in the provision of basic health care services. That such a case is currently pending in the United States Supreme Court²⁷ and raises many of the conceptual issues central to this section provides both a convenient starting point for the discussion, and a concrete example of the analytical method challenged in this essay.²⁸

In a series of recent cases expanding on the meaning of various federal laws governing the rights of the disabled,²⁹ the United States Supreme Court

discrimination against the disabled in cases involving exclusionary zoning); *Consolidated Rail Corp. v. Darrone*, 465 U.S. 624 (1984) (coverage of funded programs); *Alexander v. Choate*, 469 U.S.—, 105 S. Ct. 712 (1985) (application of "disparate impact" theory as a matter of law or regulation); *Smith v. Robinson*, 104 S. Ct. 3457 (1984) (relationship of the Education of the Handicapped Act, §§ 601, *et seq.*, 20 U.S.C. §§ 1400, *et seq.*, (1982) [hereinafter cited as E.H.A.] to Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1982) and the fourteenth amendment); *Board of Education v. Rowley*, 458 U.S. 176 (1982) (extent of rights under E.H.A.); *Southeastern Community College v. Davis*, 442 U.S. 397 (1979) (limits on reach of Section 504).

25. Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1982) provides, in relevant part:

No otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance

See *Consolidated Rail Corp. v. Darrone*, 465 U.S. 624 (1984) (federal funds need not be given with the "primary objective" of promoting employment to subject the recipient to the requirements of Section 504). The definition of the term "handicapped individual" is found in 29 U.S.C. § 706(7)(B) (1982): "the term 'handicapped individual' means * * * any person who (i) has a physical or mental impairment which substantially limits one or more of such person's major life activities, (ii) has a record of such an impairment, or (iii) is regarded as having such an impairment."

26. See, e.g., FLA. STAT. ANN. § 760.10 (West Supp. 1985); N. D. CENT. CODE §§ 14-02.4-03 to 4-06, 14-02.4-08 (1984); OHIO REV. CODE § 4112.02 (Page 1984); TENN. CODE ANN. §§ 8-50-103, -104 (1979). Unlike the federal government, the states are not constrained by the need to tie non-discrimination provisions to a funding source or some matter of federal concern such as interstate commerce, but may prohibit the discrimination directly, without reference to a jurisdictional "handle".

27. *Heckler v. American Hosp. Ass'n*, No. 84-1529, *cert. granted*, 105 S. Ct. 3475 (1985). The decision of the United States Court of Appeals for the Second Circuit in *American Hospital Association v. Heckler* is unreported, but that court relied on its decision in *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984), *aff'g* 575 F. Supp. 607 (E.D. N.Y. 1983). The decision of the district court in the *Heckler* case, which also relied on the decision in *United States v. University Hosp.*, is reported at 585 F. Supp. 541 (S.D.N.Y. 1984).

28. See *infra* notes 199-251 and accompanying text.

29. See cases cited *supra* note 24.

has pointed out that the Congressional concern which prompted their enactment was a dual one: to protect the handicapped from the discriminatory acts of others³⁰ and to eliminate what might be called "benign neglect" based on "thoughtlessness and indifference."³¹

That the Congressional concern was for both the social welfare needs and the civil rights of the disabled is critically important. Although they are related issues, they are not identical in either form or substance, and are often confused in debates over policy.³² The main point to be made here is that, to date, the Supreme Court has begun to distinguish clearly between the two in an attempt to further both policy goals without subordinating either.

Thus, in *City of Cleburne, Texas v. Cleburne Living Center, Inc.*³³ the Supreme Court ruled that the Equal Protection Clause forbids exclusionary zoning which would make it impossible for the mentally retarded to live in a neighborhood group home environment. The rationale and method of analysis is instructive, for it illustrates the Court's increasing willingness to con-

30. See *Alexander v. Choate*, 469 U.S. ___, 105 S. Ct. 712, 718-20 (1985) (holding that Section 504 would clearly cover cases of intentional discrimination against the handicapped, but refusing to hold either that the regulations promulgated under the statute are limited to such cases or that the statute necessarily comprehends the use of "disparate impact" analysis); *Consolidated Rail Corp. v. Darrone*, 465 U.S. 624 (1984) (coverage of funded programs); *Smith v. Robinson*, 104 S. Ct. 3457 (1984).

31. *Alexander v. Choate*, 469 U.S. ___, 105 S. Ct. 712, 718 & nn.12-16. (1985). The sources cited in the footnotes make it clear that the Court draws a bright line between "thoughtlessness and indifference" which, though neglecting the needs of the disabled, might be considered "benign" in that they are not intentional or "invidious". Footnote 12 is instructive:

To be sure, well-catalogued instances of invidious discrimination against the handicapped do exist. See, e.g., UNITED STATES COMMISSION ON CIVIL RIGHTS, *ACCOMMODATING THE SPECTRUM OF INDIVIDUAL ABILITIES* Ch. 2 (1983); Wegner, *The Antidiscrimination Model Reconsidered: Ensuring Equal Opportunity Without Respect to Handicap Under Section 504 of the Rehabilitation Act of 1973*, 69 CORNELL L. REV. 401, 403 n.2 (1984).

Neglect of the disabled which is intentional — such as denying food and water or necessary medical care to the ill or handicapped — would not, and should not, fall into the "benign" category. See *infra* text accompanying note 51.

32. The debate over the relationship between a "social issue" and a "civil rights issue" is one which has, of late, taken up much time and energy among my colleagues on the United States Commission on Civil Rights, and is far beyond the scope of this paper. For an expanded discussion on the differences between the two concepts, see Destro, *Equality, Social Welfare and Equal Protection*, 9 HARV. J. L. & PUB. POL'Y 51 (1986). The Supreme Court itself obliquely recognized the same distinction in *Alexander v. Choate* when it quoted the brief of the United States Solicitor General as follows: "Antidiscrimination legislation can obviously be emptied of meaning if every discriminatory policy is 'collapsed' into one's definition of what is the relevant benefit." Brief for the United States as Amicus Curiae at 29 n.36, *Alexander v. Choate*, 469 U.S. ___, 105 S. Ct. 712, 721 n.21 (1985).

33. 473 U.S. ___, 105 S. Ct. 3249 (1985).

sider statutes having an impact on the disabled on the basis of an inquiry into their consistency with the principles underlying the Equal Protection Clause, rather than on the basis of a blanket constitutional standard which gives greater weight to judicial sensibilities than it does to legislative judgments.

The Court began its discussion of the constitutional standards which govern legislation having an adverse impact on the mentally retarded with a review of the general standards which are applicable to cases raising Equal Protection claims, and held that mental retardation is not a "quasi-suspect classification calling for a more exacting standard of judicial review than is normally accorded economic and social legislation."³⁴ By doing so, the Court highlighted the obvious social and constitutional concerns which motivated its conclusions:

First . . . those who are mentally retarded have a reduced ability to cope with and function in the everyday world. . . . [T]hey range from those whose disability is not immediately evident to those who must be constantly cared for. They are thus different, immutably so, in relevant respects, and the states' interest in dealing with and providing for them is plainly a legitimate one. How this large and diversified group is to be treated under the law is a difficult and often a technical matter, very much a task for legislators guided by qualified professionals and not by the perhaps ill-informed opinions of the judiciary. Heightened scrutiny inevitably involves substantive judgments about legislative decisions, and we doubt that the predicate for such judicial oversight is present where the classification deals with mental retardation.

* * *

Because mental retardation is a characteristic that the government may legitimately take into account in a wide range of decisions, and because both state and federal governments have recently committed themselves to assisting the retarded, we will not presume that any given legislative action, even one that disadvantages retarded individuals, is rooted in considerations that the Constitution will not tolerate.³⁵

Although the practical impact of the Court's decision respecting the constitutional standard of review was to make it less likely that the judiciary will be able to substitute its judgment for that of the legislature, the majority opinion makes it clear that "refusal to recognize the retarded as a quasi-suspect class does not leave them entirely unprotected from invidious dis-

34. *Id.* 105 S. Ct. at 3255-56 (1985). For a general discussion of these standards see *supra* note 16.

35. *Cleburne*, 105 S. Ct. at 3258 (footnotes omitted).

crimination.”³⁶ The decision permits courts to focus on the reasons asserted for the challenged unequal treatment and to analyze whether the discriminatory policy is actually related to a legitimate state purpose. Having performed such an analysis in *Cleburne*, there could be little doubt that the reason for the discriminatory treatment was “the negative attitude of the majority of the property owners located within 200 feet of the . . . facility, as well as the fears of elderly residents of the neighborhood.”³⁷ In short: “an irrational prejudice against the mentally retarded.”³⁸

A similar analytical form was employed in two other recently decided cases: *Alexander v. Choate*,³⁹ and *Smith v. Robinson*.⁴⁰ In *Alexander v. Choate*, for example, the Court, in a unanimous decision, distinguished carefully among the types of civil rights law theories which would be applicable in cases brought under Section 504 of the Rehabilitation Act of 1973,⁴¹ and held that since “discrimination against the handicapped is primarily the result of apathetic attitudes rather than affirmative animus[,] . . . much of the conduct that Congress sought to alter in passing the Rehabilitation Act would be difficult if not impossible to reach were [it] construed to proscribe only conduct fueled by a discriminatory intent.”⁴²

The effect of the ruling in *Choate* is to distinguish between the goal of requiring equal rights for the disabled and providing services designed to meet their special needs.⁴³ Although the exact nature of needs which are beyond the “reasonable accommodation” requirement of Section 504 remains undefined, the facts in both *Choate* and *Southeastern Community College v. Davis*,⁴⁴ which was reaffirmed in *Choate*,⁴⁵ do cast some light on this question.

In *Davis*, the plaintiff was a student with a major hearing disability who sought admission to a college training program for registered nurses. The modifications she sought — full-time, personal supervision whenever she attended patients, and elimination of all clinical courses — would have, in the Court’s view, “compromised the essential nature of the college’s nursing program” without providing her with the benefits she sought,⁴⁶ for even

36. *Id.* at 3258.

37. *Id.* at 3259.

38. *Id.* at 3260.

39. 469 U.S.—, 105 S. Ct. 712 (1985).

40. 104 S. Ct. 3457 (1984).

41. 29 U.S.C. § 794 (1982).

42. 105 S. Ct. 712, 718-19.

43. *See infra* note 51 and accompanying text.

44. 442 U.S. 397 (1979).

45. 105 S. Ct. at 720-21.

46. *Southeastern Community College v. Davis*, 442 U.S. 397, 413-14 (1979).

with the training and supervision, she would have been incapable of safely performing her duties as a nurse.⁴⁷ In *Choate* the issue was whether the State of Tennessee could, in an attempt to reduce costs, lower the number of days for which it would reimburse hospitals for services rendered to Medicaid patients per fiscal year from twenty to fourteen. The plaintiffs in *Choate* argued that the reduction in benefits would have a far greater impact on the handicapped than it would on those without disabilities, and that, given the special needs of the disabled, the State should not be permitted to impose a durational limitation at all.⁴⁸ The Court rejected this contention, holding that a facially neutral limitation on the amount of services available to both handicapped and non-handicapped alike simply was not discriminatory, and that Section 504 "does not require the State to alter [its] definition of the benefit being offered simply to meet the reality that the handicapped have greater medical needs."⁴⁹

Seen in context with *Cleburne*, the holding in *Choate* to the effect that "[t]he balance struck . . . requires that an otherwise qualified handicapped individual must be provided with meaningful access to the benefit that the grantee offers"⁵⁰ means simply that the disabled must be offered at least the same level of services as are offered to those without disabilities. Taken together with the holding in *Davis* that the handicapped individual must be able to reap the intended benefit of the program or service offered, there can be no doubt that, with respect to access to the most basic types of medical care and treatment (such as food and water),⁵¹ the handicapped have the

47. Notably, the plaintiff in *Davis* would not have been capable of safely performing the duties of a registered nurse even with full-time supervision. *Id.* at 403, 408 n.8; *Choate*, 105 S. Ct. at 720.

48. The evidence in the district court showed that in the 1979-1980 fiscal year 27.4% of all Medicaid-eligible handicapped users of hospital services required more than fourteen days of care, while only 7.8% of non-handicapped users required services of the same duration. *Choate*, 105 S. Ct. at 715. Although the district court had dismissed the complaint on the grounds that the disproportionate impact on the handicapped was "not the type of discrimination that § 504 was intended to proscribe[.]" a divided panel of the United States Court of Appeals for the Sixth Circuit had held that such evidence made out a prima facie violation of Section 504. The State was therefore instructed to prove either that "alternative plans that would achieve the State's legitimate cost-saving goals with a less disproportionate impact on the handicapped" were unavailable, or "a substantial justification for the adoption of the plan with the greater discriminatory impact." *Id.* at 716 & n.6 quoting both the decision of the district court and the court of appeals in *Jennings v. Alexander*, 518 F. Supp. 877, 881 (M.D. Tenn. 1981), *rev'd*, 715 F.2d 1036, 1045 (6th Cir. 1983), *rev'd sub nom.* *Alexander v. Choate*, 105 S. Ct. 712 (1985).

49. *Choate*, 105 S. Ct. at 722.

50. *Id.* at 721.

51. The benefit itself, of course, cannot be defined in a way that effectively denies otherwise qualified handicapped individuals the meaningful access to which they are

same rights to equal treatment as those without disabilities.⁵²

Dealing with Special Needs: Equality vs. Social Welfare

Because the disabled and the elderly, like the poor and others suffering from social disadvantage or a legacy of past discrimination, often have special needs not shared by the community at large, the legal standards applicable to classifications which single them out for special treatment — sometimes referred to as “affirmative action”⁵³ — designed to address their needs have prompted a good deal of debate in the literature and in the cases. The most recent case dealing with this issue in the context of disability rights was *Smith v. Robinson*,⁵⁴ a case in which the Supreme Court resolved a dispute over the relationship among the Education of the Handicapped Act,⁵⁵ Section 504 of the Rehabilitation Act of 1973,⁵⁶ and the Due Process and Equal Protection Clauses of the Fourteenth Amendment.⁵⁷

Although the dispute in *Smith* centered on the question of whether attorney’s fees were available under the various statutory and constitutional provisions cited as a basis for the requirement that handicapped children be provided “free appropriate public education”,⁵⁸ the case is important for the

entitled; to assure meaningful access, reasonable accommodations in the grantee’s program or benefit may have to be made.

Choate, 105 S. Ct. at 721 (footnote omitted).

The significance of this holding is that attempts to define the benefit in such a manner as to justify depriving it from a disabled person must be looked at with a jaundiced eye. The standard is whether or not the disabled person can reap the same benefit as one who is able-bodied or has a good prognosis for recovery. Food and water, whether administered by mouth or by other means, perform the same function for the able-bodied as they do for the disabled: they are the basic essentials of life. Thus, the test is *not* whether the substance administered will “cure” the patient, but rather the *function* it performs, and whether that function is identical in both cases. See *supra* text accompanying note 43. Compare *infra* text accompanying notes 164, 219-33.

52. See *Choate*, 105 S. Ct. at 721-25. In the other recent case involving the rights of the disabled under Section 504, *Consolidated Rail Corp. v. Darrone*, 465 U.S. 624, 631-34 (1984), the Court ruled that any recipient of federal financial assistance, not just those who receive aid designed to promote employment, is covered by the equality of treatment mandate of that statute.

53. *Smith v. Robinson*, 104 S. Ct. 3457, 3473 (1984) (citing *Southeastern Community College v. Davis*, 442 U.S. 397, 411-12 (1979)).

54. 104 S. Ct. 3457 (1984).

55. Education of the Handicapped Act §§ 601 *et seq.*, 20 U.S.C. §§ 1400 *et seq.* (1982) [hereinafter cited as E.H.A.].

56. 29 U.S.C. § 794 (1982).

57. U.S. CONST. amend. XIV, § 1.

58. Education of the Handicapped Act §§ 601 *et seq.*, 20 U.S.C. §§ 1400 *et seq.* (1982). See generally *Board of Educ. v. Rowley*, 458 U.S. 176 (1982). Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 and specific regulations promulgated by the Department of Education pursuant to the Act, 34 C.F.R. § 104.33(c)(3) (1985), 42 Fed. Reg. 22,676 (1977),

distinctions it draws between the remedies available under the various constitutional and statutory provisions which are available to protect the rights of the disabled. In short, the Supreme Court held that where Congress enacts a comprehensive statutory program which is designed to accommodate the rights and needs of the handicapped, it is inappropriate for the judiciary either to substitute its own approach for protecting such rights under an open-ended constitutional standard such as Equal Protection,⁵⁹ or to stretch the meaning of an overlapping provision such as Section 504 of the Rehabilitation Act of 1973⁶⁰ beyond its goal of providing "equal access" to services already provided to those without disabilities.⁶¹ The majority opinion does make it clear, however, that where a state does provide "services beyond those required [by Congress], but discriminatorily denie[s] those services to a handicapped child, [Section] 504 would remain available . . . as an avenue of relief."⁶²

as well as the Due Process and Equal Protection Clauses of the fourteenth amendment, have also been relied upon as independent bases for such a requirement. A thorough discussion of the standards to be applied in cases where Congress has provided comprehensive enforcement mechanisms for enforcement of private rights, but the parties assert their more general rights under 42 U.S.C. § 1983 (1982) is beyond the scope of this essay. See *Middlesex County Sewerage Auth. v. National Sea Clammers Ass'n*, 453 U.S. 1 (1981). The attorney's fees dispute involved in *Smith v. Robinson* rests on that question and turns on a determination respecting Congress' intent when it enacted the various laws which protect the disabled from discrimination and assure that they receive public services appropriate to their needs. The non-discrimination provisions contain authority for an award of attorney's fees to the "prevailing party", see Section 505(b) of the Rehabilitation Act of 1973, 29 U.S.C. § 794(a)(b) (Supp. 1985) (governing claims under Section 504); 42 U.S.C. § 1988 (1982) (governing general civil rights and constitutional claims under 42 U.S.C. §§ 1981-85) (1982), but E.H.A., which guarantees both the provision of services and the procedures to be followed by those seeking them, does not. See *Smith v. Robinson*, 104 S. Ct. 3457, 3465-74 (majority opinion), 3475 (Brennan, Marshall, & Stevens, JJ., dissenting) (1984).

59. *Smith v. Robinson*, 104 S. Ct. at 3472. Although the Court has held that there are other means available to protect constitutional rights in the absence of an express grant of statutory protection by Congress, see *id.* at 3469-70 n.15, the primary method for doing so is by lawsuit under 42 U.S.C. §§ 1981-85 (1982) which authorize redress for denials of federal constitutional and statutory rights.

60. 29 U.S.C. § 794.

61. *Smith v. Robinson*, 104 S. Ct. at 3473. The majority expressly disavowed any opinion on the question of whether or to what extent Section 504 also confers a substantive right to "free appropriate public education" similar or identical to that provided under E.H.A., but did note that none of the parties to the case had made the "suggestion that § 504 adds anything to petitioners' substantive right to a free appropriate public education," other than the possibility that Section 504 could be used to circumvent E.H.A. administrative procedure and go directly to court, and obtain damages and attorney's fees, neither of which are provided by that statute. *Id.* at 3473-74 & nn.22-24.

62. *Id.* at 3473 n.22.

Read together, *Cleburne*,⁶³ *Robinson*,⁶⁴ and *Choate*⁶⁵ stand for the proposition that the disabled are entitled, at a minimum, to equal treatment at the hands of government and those who receive federal funds whenever they stand to receive the intended benefits of a program or activity offered to those without disabilities. While inequities which do affect the disabled need only be rationally related to the government's asserted purpose, the Court will intervene whenever "an irrational prejudice",⁶⁶ rather than an attempt to accommodate basic human needs,⁶⁷ is found to be the starting point for the legislative enactment. Taken at face value, the proposition would seem to most observers to contain not only a fair and common-sense oriented approach to the rights of the disabled, but also a healthy respect for the limits of judicial responsibility to correct perceived legislative shortcomings.⁶⁸ The difficulty, however, is that when courts are faced with what might be called "hard cases"⁶⁹ involving the elderly, incompetent or disabled there is a ten-

63. *City of Cleburne, Texas v. Cleburne Living Center, Inc.* 473 U.S. —, 105 S. Ct. 3249 (1985).

64. *Smith v. Robinson*, 104 S. Ct. at 3457.

65. *Alexander v. Choate*, 469 U.S.—, 105 S. Ct. 712 (1985).

66. *Cleburne*, 105 S. Ct. at 3260.

67. *Id.* at 3259. See *Smith v. Robinson*, 104 S. Ct. at 3470.

68. The debate over whether the Court should read remedial statutes such as E.H.A. as broadly as possible, relying if necessary on other, more broadly phrased-statutory language such as 42 U.S.C. § 1983 (1982), is beyond the scope of this paper. But the implicit assumption of some judges and commentators to the effect that when the issue is arguably one which does not expand the ambit of civil rights, the judiciary must retain ultimate and largely unfettered control, see, e.g., *Cleburne*, 473 U.S. —, 105 S. Ct. at 3263 (1985) (Marshall, Brennan & Blackmun, JJ., concurring and dissenting); *Smith v. Robinson*, 104 S. Ct. at 3474, 3476-79 (Brennan, Marshall & Stevens, JJ., dissenting); *Grove City College v. Bell*, 465 U.S. 555, 581, 599-604 (1984) (Brennan and Marshall, JJ. concurring and dissenting), seems, to this writer, to go far beyond the constitutionally-mandated separation of powers which guarantees the democratic process. Thus, the question of whether the decision in *Middlesex County Sewerage Auth. v. National Sea Clammers Ass'n*, 453 U.S. 1 (1981) should be read to limit the authority of courts to expand civil rights remedies in the face of what appear to be implicit, good-faith limits on those remedies as was the situation in *Smith* and *Choate*; or whether the Court was really bound in *Grove City College v. Bell* to apply the express, but more limited, "program or activity" language written by Congress, rather than the far-broader administrative interpretation urged by some civil rights advocates, are not really "civil rights" issues in the traditional sense at all. They are policy arguments which proceed from the assumption that judicial authority can substitute for legislative action which cannot or will not change substantive legal provisions deemed by the litigants or the court to be inadequate or archaic in light of the perceived current needs of the legal system. See generally G. CALABRESI, A COMMON LAW FOR THE AGE OF STATUTES (1982). Compare *infra* notes 102, 201-04 and accompanying text. Such reasoning has the potential to erode even further the constitutional doctrines of separation of powers and federalism because it does so in the name of a "higher good" (civil rights). For additional reflections on this topic as it relates to the current controversy over alleged limits on the power and duty of government to protect the disabled, the handicapped infant and the defenseless elderly, see Part III and Conclusion.

69. See cases discussed *infra* notes 223, 227-29 and accompanying text. These may be

dency to justify or, more commonly, to ignore both "irrational" and "rational"⁷⁰ prejudice on moral, legal, ethical, and constitutional grounds. That they are also beginning to do so in cases involving the interests of the mentally retarded⁷¹ is but a logical outgrowth of the reasoning process employed.

II. WHOM SHOULD THE LAW PROTECT? OF PRINCIPLED OR FUNCTIONAL DEFINITIONS OF THE LEGAL CONCEPT OF "PERSON"

Introduction

Over the past fifteen years, America has witnessed a debate within academic and professional circles on the issue of whether legal policies governing bioethical questions should be governed by a "quality-of-life" ethic or a "sanctity-of-life" ethic.⁷² The debate is not a new one,⁷³ but overt discus-

described as "hard cases" because they involve both judicial scrutiny of close medical questions, and judicial attempts to mesh the requirements of a legal system which is designed to protect individual life with a developing ethic which holds death to be a humane alternative when the prognosis is especially dim. See *infra* notes 216, 230, 246 and accompanying text.

70. "Rational" prejudice can be distinguished from "irrational" prejudice by reference to the *reasons* stated by those affected by it. A visceral, but intense fear of racial minorities based on little or no experience might be termed "irrational" and is probably the easiest to overcome. Experience may prove it to be unfounded. "Rational" prejudice, on the other hand, is well thought out: a matter of conscious judgment. Nazi hatred of Jews and Gypsies was, if anything, coldly rational and pragmatic. It reflected the conscious choice of a subjective, utilitarian ethic which negated individual rights in order to "purify" the races. Its danger to society lay in its cold-bloodedly rational rejection of the inherent equality of human persons, and its assertion of a eugenically based societal right to eliminate those whose race, physical condition or mental capacity was deemed to be inferior. See generally F. WERTHAM, *A SIGN FOR CAIN: AN EXPLORATION OF HUMAN VIOLENCE* chs. 8, 9 (1966); W. BRENNAN, *1 MEDICAL HOLOCAUSTS* chs. 2, 3 (1980).

71. See, e.g., *In re Infant Doe*, *supra* note 11.

72. One of the best early statements of the difference between the two ethical viewpoints appeared in a 1970 editorial in *California Medicine*, the journal of the California Medical Association. While it conceded that the "traditional Western ethic has always placed a great emphasis on the intrinsic worth and equal value of every human life," it suggested that the time was right for the adoption of a "new ethic" which would adopt a more relativistic approach toward the valuation of individual human lives. Editorial, *A New Ethic for Medicine and Society*, CAL. MED., Sept., 1970, at 68. It also accurately noted that "[m]edicine's role with respect to changing attitudes toward abortion will be a prototype of what is to occur." *Id.* It went on to predict that "[o]ne may anticipate further developments of these roles as problems of birth control and birth selection are extended, inevitably to death selection and death control, whether by the individual or by society, and further public and professional determination of when and when not to use scarce resources." *Id.* These views were echoed 13 years later in the context of what the *California Medicine* editorial called "death selection" by Peter Singer, who wrote that "[t]he ethical outlook that holds human life to be sacrosanct — I shall call it the 'sanctity-of-life view' — is under attack. The first major blow . . . was the spreading acceptance of abortion, and that [w]e can no longer base our ethics on the idea that

sion of the issue in reported cases is of relatively recent vintage, and shows that the process has reached the point where the academic and professional debates have begun to influence the actual direction of public policy. That rapid advances in medical technology have accelerated the process is obvious, but it was clearly under way in such traditional areas as abortion⁷⁴ and euthanasia⁷⁵ long before the development of the advances in medical technology so often cited as current justification for a shift in our ethical approach.⁷⁶

The subject of this section, then, will be the ongoing process by which a "quality-of-life" ethic is being adopted in place of the original natural rights ethic which has governed American law since the Declaration of Independence. It will be argued that the primary method being utilized by courts and commentators to effect the change from the original natural rights/"sanctity-of-life" ethic to one which rests upon the quality of a given life to

human beings are a special form of creation . . ." *Id.* Commentary, *Sanctity of Life or Quality of Life?*, 72 *Pediatrics* 128 (July 1983).

The key to valuation of individual human life, in Singer's view, is that "we may continue to see normal members of our species as possessing greater capacities of rationality, self-consciousness, communication and so on, than members of any other species, but we will not regard as sacrosanct the life of each and every member of our species, no matter how limited its capacity for intelligent or even conscious life may be."

73. See generally D. Kevels, *Annals of Eugenics: A Secular Faith*, *The New Yorker*, Oct. 8, 1984, at 51 (Part I), Oct. 15, 1984, at 52 (Part II), Oct. 22, 1984, at 51 (Part III), Oct. 29, 1984, at 92 (Part IV).

74. See, e.g., COLO. REV. STAT. § 40-2-50(4) (1963 & Supp. 1967), 1967 COLO. SESS. LAWS Ch. 190 at § 284 (permitting eugenic abortions); *Gleitman v. Cosgrove*, 49 N.J. 22, 227 A.2d 689 (1967) (rejecting the tort of "wrongful birth" based on the birth of a child with a disability); MODEL PENAL CODE § 207.11 (1959) (permitting eugenic abortion). See generally NATIONAL COMMISSION FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH, REPORT AND RECOMMENDATIONS: RESEARCH ON THE FETUS (1975), reprinted in 40 Fed. Reg. 33,530 (1975) (partially codified at 45 C.F.R. §§ 46.101-301 (1976)); Symposium, *The Report and Recommendations of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Research on the Fetus*, 22 VILL. L. REV. 297 (1977); Morrison, *Implications of Prenatal Diagnosis for the Quality of, and Right to Human Life*, in *Biomedical Ethics and the Law* (J. Humber & R. Almeder eds.) The current state of the law respecting these issues is discussed *infra* notes 139, 141, 249.

75. See, e.g., DEATH, DYING AND EUTHANASIA (D. Horan and D. Mall eds. 1977); D. HUMPHREY, LET ME DIE BEFORE I WAKE (1981); BENEFICENT EUTHANASIA (M. Kohl ed. 1975); P. RAMSEY, ETHICS AT THE EDGE OF LIFE (1978); Sacred Congregation for the Doctrine of the Faith, *Declaration on Euthanasia* (Vatican City, May 5, 1980); Alexander, *Medical Science Under Dictatorship*, 241 NEW ENG. J. MED. 39 (1949); Rachels, *Active and Passive Euthanasia*, 292 NEW ENG. J. MED. 78 (1975); Kamisar, *Euthanasia Legislation: Some Non-Religious Objections*, 42 MINN. L. REV. 969 (1958).

76. See generally J. LYON, PLAYING GOD IN THE NURSERY (1985); HOW BRAVE A NEW WORLD? (R. MCCORMICK ed. 1981); Deciding to Forego Life-Sustaining Treatment *supra* note 8; Scott, *Legal Implications and Law Making in Bioethics and Experimental Medicine*, 1 J. Contemp. Health L. & Pol'y 47 (1985).

society is a functional definition of what it means to be a human person. It will begin with an analysis of constitutional and other legal sources, and conclude with an argument for rejecting such "functional" definitions. As a result, Part II will examine two distinct types of arguments: legal arguments based on the present state of the law governing the rights of all individuals, and legal policy arguments which are directed toward what the ethic governing the law affecting those who are helpless or disabled should be.⁷⁷

The distinction between "what is" and "what should be" in the law is often a fine one. It is quite frequently overlooked in practice whenever there are strong pressures for courts to reach a given result (i.e. "to do what is right") even though the law as written may compel a different outcome.⁷⁸ This is especially true in the American constitutional and common law traditions, where judges have taken for themselves the authority to adjust the governing legal principles by continually restating "what the law is"⁷⁹ on a

77. It has been argued that terms such as "right to life" . . . 'quality of life' and 'euthanasia' have been used in such conflicting ways that their meanings, if they ever were clear, have become hopelessly blurred" and should be relegated to the status of "empty rhetoric", *DECIDING TO FOREGO LIFE - SUSTAINING TREATMENT*, *supra* note 8, at 24-26. While it is true that the terms may have different meanings to different persons, it is also clear that their meanings are considerably sharpened when they are understood in terms of the ethical formulation of the person using the term. Thus, they are by no stretch of the imagination "empty rhetoric" when the ethic on which they are based is made clear. If, for example, the term "quality-of-life" is used in a eugenic or functional sense, it carries a far different meaning than if it is used in a social, environmental, or economic sense. Similarly, the term, "right to life" can scarcely be described as "empty rhetoric" when the American Constitution and Declaration of Independence explicitly mention it. U.S. CONST. amends. V, XIV. It is the terms for which no clear ethical referent have been established, such as "right to die," or "right to privacy," or "death-with-dignity" which can be classified as "empty rhetoric" unless and until their governing ethic is made clear. For a recent examination of the same problem with respect to the definition of "equality" and "affirmative action" in the area of civil rights see generally Destro, *Equality, Social Welfare and Equal Protection*, 9 HARV. J. L. & PUB. POL'Y 51 (1986).

78. See, e.g., *Akron v. Akron Center for Reproductive Health*, 462 U.S. 416, 420 n.1 (1983); *Grove City College v. Bell*, 465 U.S. 555, 599 (1984) (Brennan & Marshall, JJ., concurring and dissenting); *Regents of the Univ. of California v. Bakke*, 438 U.S. 265 (1978); *Fullilove v. Klutznick*, 448 U.S. 448 (1980); *id.* at 522 (Stewart and Rehnquist, JJ., dissenting); *id.* at 532 (Stevens, J., dissenting).

79. Perhaps the most famous statement espousing this position with respect to American constitutional law was contained in a 1907 speech by the late Chief Justice Charles Evans Hughes: "We are under a Constitution, but the Constitution is what the judges say it is . . ." Speech at Elmira, New York (May 3, 1907) reprinted in BARTLETT, *FAMILIAR QUOTATIONS* 864b (14th ed. 1968). On the question of judicial review in constitutional law, see generally *Immigration and Naturalization Service v. Chadha*, 462 U.S. 919 (1983) (majority opinion per Burger, C.J.) (citing *Marbury v. Madison*, 5 U.S. 1 (Cranch) 137 (1803)). For a discussion of the common law function of judicial review see, e.g., G. CALABRESI, *A COMMON LAW FOR THE AGE OF STATUTES* (1982) Compare Rees, *Cathedrals Without Walls: A View from the Outside* (Book Review) 61 TEX. L. REV. 347 (1982); See also J. ELY, *DEMOCRACY AND DISTRUST* (1980); E. LEVY, *AN INTRODUCTION TO LEGAL REASONING* (1949); L. LUSKY, *BY WHAT RIGHT?* (1975). An extended discussion of the differences between the constitutional

case-by-case basis. It will be argued that in situations where there is doubt that judicial intervention is warranted on behalf of what the law arguably "should be",⁸⁰ the ethic which governs the judicial approach from the outset is the critical factor; for the incremental nature of the legal process itself encourages the submission of new cases which will seem but a short step from the last.

Thus in order to set the legal backdrop for a discussion of the impact that "quality-of-life" arguments can have on the direction of existing law, Part I of this essay focused on the constitutional and legal principles which presently govern the rights of the handicapped and aged to equal treatment before the law.⁸¹ It argued that these laws and principles are present legal formulations which are binding on all segments of society, including courts, until changed by appropriate means, and that they are rooted in a natural rights ethic which condemns any "invidious" focus on disability, race, age, sex, religion or national origin as irrelevant considerations in determining the intrinsic worth of a human person. Part II will argue that "quality-of-life" arguments, by contrast, are rooted in a functional ethic whose focus is the worth of the individual as judged externally, by reference to what he or she can do or contribute to the society in which they are a part; that such an approach is inherently inconsistent with the legal principles identified in Part I; and that its adoption will result in the gutting of the ethic on which those principles rest.

and common-law traditions is beyond the scope of this essay. It should be noted, however, that their fundamental difference lies in the fact that constitutions are "supreme law" which, in theory, can only be changed in accordance with the provisions set out in the constitution itself. See, e.g., U.S. CONST. art. V, art. VI, § 2. The common-law, on the other hand, is judge-made and is subject to continuous revision at the hands of the judiciary which made it, and legislatures are free either to accept, modify or reject it through codification of legislative policy.

80. Compare *Frontiero v. Richardson*, 411 U.S. 677, 678 (1973) (opinion of Brennan, Douglas, White & Marshall, JJ.) with *id.* at 691 (Powell & Blackmun, JJ., and Burger C.J., concurring). The abortion decisions, *Roe v. Wade*, 410 U.S. 113 (1973) and *Doe v. Bolton*, 410 U.S. 179 (1973) are a case in point. The cases are rarely, if ever, defended as appropriate instances for the exercise of the power of judicial review as a matter of constitutional law, see, e.g., Brief Amicus Curiae for the United States, *Thornburg v. American College of Obstetricians and Gynecologists*, 737 F.2d 283 (3d Cir. 1984), *juris. postponed*, 105 S. Ct. 2015 (1985); Ely, *The Wages of Crying Wolf: A Comment on Roe v. Wade*, 82 YALE L.J. 920 (1973); Epstein, *Substantive Due Process by Any Other Name: The Abortion Cases*, 1979 SUP. CT. REV. 159; in fact, most of the commentary defending them argues that they are correct as a matter of public policy. See, e.g., Brief Amicus Curiae of Senator Bob Packwood, *et al.*, *Thornburgh v. American College of Obstetricians and Gynecologists*, 737 F.2d 283 (3rd Cir. 1984), *juris. postponed*, 105 S. Ct. 2015 (1985). See also *Akron v. Akron Center for Reproductive Health*, 462 U.S. 416, 420 n.1 (1983) (refusing to consider their correctness as a matter of constitutional law on grounds of *stare decisis*); *Harris v. McRae*, 448 U.S. 297, 326 (1980); *id.* at 337 (Marshall, J., dissenting).

81. See *supra* notes 18-68 and accompanying text.

Examination of the cases demonstrates that quality-of-life arguments are invariably put forth as the only "reasonable" solution to a hard case created by a given medical prognosis or other set of medical circumstances. Because such arguments derive their persuasive force from the uniquely difficult facts of individual cases rather than from any argument that they are but the logical extension of long-established and accepted legal principles,⁸² a "case-by-case" approach to decision-making which accepts the quality-of-life ethic as its starting point will inevitably have a negative incremental effect on existing law resting on a natural rights ethic. It does so by permitting exceptions to the general, "natural rights" rule which are based on quality-of-life principles.

Given the importance of *stare decisis* to common-law and constitutional policy-making,⁸³ the exception or extension of the law which was legitimated by the decision in the prior case becomes the starting point for each new case.⁸⁴ The philosophy which motivated the creation of the prior exceptions from the original rule becomes the philosophical underpinning for the development of new exceptions or modifications of the rule. Any attempt to reimpose the original, pre-existing rule, or to limit the advance of the newly established legal principle, is seen as a "step-backward" into an ethically or

82. See, e.g., *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976).

83. But see *Akron v. Akron Center for Reproductive Health*, 462 U.S. 416, 420 n.1 (1983) (noting that reliance on *stare decisis* is problematic in constitutional law when it is argued that the prior decision is erroneous as a matter of law).

84. A linear review of the cases produces an extraordinarily clear illustration of this principle. In the context of medical treatment for incompetents, *In re Quinlan*, 70 N.J. 10, 355 A.2d 647 (1976) dealt with the case of disconnecting a respirator supporting a comatose patient with a view towards letting nature take its course. Nine years later, the New Jersey Supreme Court decided *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985) which dealt with the case of an incompetent patient who was not comatose, but in a waking "vegetative state." The plea for relief in *Conroy*, however, was that nature needed to be "helped" by withdrawing food and fluids. Death would then occur, not because of the patient's condition, but from dehydration and starvation. The *Conroy* case is discussed in greater detail *infra* text accompanying notes 153-83.

The same progression holds true with respect to abortion. When the Supreme Court decided *Roe v. Wade*, 410 U.S. 113 (1973) it claimed that its decision was limited in scope. By 1985, however, the holding had been expanded to the point where there were practically no limitations on abortions whatever. See *Akron v. Akron Center for Reproductive Health*, 462 U.S. 416 (1983) (striking second trimester restrictions approved in *Roe*); *Planned Parenthood of Central Missouri v. Danforth*, 428 U.S. 52 (1976) (striking fathers' and parents' rights); *Thornburgh v. American College of Obstetricians and Gynecologists*, 737 F.2d 283 (3d Cir. 1984), *juris. postponed*, 105 S. Ct. 2015 (1985) (striking legislation protecting unborn children after viability). More importantly, *Roe* was cited by one district court as justification for a constitutional right of parents to refuse treatment for infants born with disabilities. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 402-03 (D.D.C. 1983) (dictum).

legally less desirable formulation of public policy.⁸⁵

It is, therefore, critically important to distinguish between the demands of existing law, which speaks with the force of present authority, and the concerns of ethics (or ethicists) which speak to what "ought to be" as a matter of correct behavior in a given case.⁸⁶ Established laws are not the equivalent of moral principles or ethical norms, although it is possible to make moral and ethical arguments to support or attack them;⁸⁷ they are legal rules which bind both courts and citizenry unless and until changed through legally permissible means.⁸⁸ Ethical or moral arguments to the effect that given legal rules should be changed to reflect a normative judgment other than that reflected in current law will not suffice as a rationale for judicial intervention on constitutional grounds to change existing policy. When seen in their proper legal and constitutional context, arguments made by ethicists in litigation challenging existing law on constitutional grounds beg the all-important legal questions: "changed how, and by whom?"⁸⁹ They also miss

85. Compare, e.g., Brief Amicus Curiae of the United States, *Thornburgh v. American College of Obstetricians and Gynecologists*, 737 F.2d 283 (3d Cir. 1984), *juris. postponed*, 105 S. Ct. 2015 (1985) (arguing that the theory of federalism—or, more properly, the rejection of federalism—explicit in *Roe* should be rejected); and Brief Amicus Curiae of Senator Gordon J. Humphrey, et al., *Thornburgh v. American College of Obstetricians and Gynecologists* (arguing that the Court's use of history and scientific theory in *Roe* was wrong and should be repudiated) with Brief Amicus Curiae of Senator Bob Packwood, et al. at 10, *Thornburgh v. American College of Obstetricians and Gynecologists*, and *Diamond v. Charles*, No. 84 1379 (United States Sup. Ct. pending) (arguing that since *Roe v. Wade* was "a natural outgrowth of a gradual process of legal evolution" rejection of the theory on which the case is based "would not be merely a restoration of the status quo ante but a revocation of the very principles from which [it] sprang. . . . [It] would then be not just a significant step backwards, [citation omitted] but a repudiation of the 50-year path along which this Court located its 1973 abortion ruling."

The same phenomenon has occurred in the context of affirmative action and equal protection. Notwithstanding its general rule that government-sponsored racial preferences are *per se* unconstitutional under the Equal Protection Clause, U.S. CONST. amend. XIV, § 1, the Supreme Court has been unwilling to extend that rule to government-sponsored racial preferences which are said to be "remedial" or "benign." *Fullilove v. Klutznick*, 448 U.S. 448 (1980); *Regents of the Univ. of Cal. v. Bakke*, 438 U.S. 265 (1978). Setting aside the question of whether a racial preference can ever be "benign," it seems clear from the cases that the lower courts have translated the Court's unwillingness to take a principled stand against all forms of racial discrimination as approving the concept that government-sponsored racial preferences are permissible in the absence of a constitutional violation requiring a remedy for an identifiable class of victims. See, e.g., *Firefighters Local Union No. 1784 v. Stotts*, 467 U.S. 561 (1984), *rev'g*, 679 F.2d 541 (6th Cir. 1982); *Wygant v. Jackson Bd. of Educ.*, 746 F.2d 1152 (6th Cir. 1984), *cert. granted*, 105 S. Ct. 2015 (1985).

86. Compare McCormick, *Moral Argument and Christian Ethics*, 1 J. CONTEMP. HEALTH L. & POL'Y 3, 13-14, 17-18 (1985) [hereinafter cited as *Moral Argument and Christian Ethics*].

87. *Accord id.* at 10-11.

88. U.S. CONST. art. VI, § 2. Compare Calabresi and Rees, *supra* note 79.

89. *Cf. Harris v. McRae*, 448 U.S. 297, 326 (1980).

the central point from a lawyer's perspective: the existing rights of the individual whose treatment is the subject of their ethical concerns. The rights of this person alone — or more properly, the duty of those charged with his or her care within the framework of a legal system which imposes on the State the duty of providing equal treatment for each person, regardless of age or handicap — should be the sole focus of the inquiry.⁹⁰

Were the ethical arguments for a change in legal or constitutional standards to be made in legislative debates seeking statutory or constitutional change, they would be correctly targeted. But given the persuasive force of moral and ethical arguments and the desire of judges to reach the "just" result, even if marginally inconsistent with established law,⁹¹ begging these questions and missing the central point⁹² encourages a gradual erosion of both the carefully crafted separation of powers which lies at the root of the

90. See *supra* text accompanying notes 14-68 and *infra* text accompanying notes 199-233.

91. See, e.g., *Firefighters Local Union No. 1784*, 467 U.S. 561 (1984) (arguable inconsistency with 42 U.S.C. § 2000e-2(h) (1982)); *Fullilove v. Klutznick*, 448 U.S. 448 (1980) (arguable inconsistency with equal protection component of fifth amendment Due Process Clause); *United Steelworkers of America v. Weber*, 443 U.S. 193 (1979) (arguable inconsistency with 42 U.S.C. §§ 2000e-2(a),(d) (1982)); *United States v. Univ. Hosp.*, 729 F.2d 144 (2d Cir. 1984), *cert. granted*, 53 U.S.L.W. 3881 (U.S. 1985) (No. 84-1529) (arguable inconsistency with 29 U.S.C. § 794 (1982)); *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985) (arguable inconsistency with N.J. STAT. ANN. § 52:27G-1 (West Supp. 1985-86)).

92. See *Moral Argument and Christian Ethics*, *supra* note 86, at 13 for an interesting criticism of "poor moral arguments in contemporary discourse." Father McCormick states:

[P]oor arguments that are accepted not only establish nothing, they leave the resultant conclusions entrenched. Both of these considerations are formidable obstacles to the progress of Christian ethics. Most of the analyses that deserve the title "poor" or "invalid" fit into either of two categories *petitio principii* (begging the question), or *ignorantia elenchi* (missing the point). Clearly these failures very frequently overlap and interpenetrate each other. That is, one who begs the question misses the point; and one who misses the point begs the question.

The same criticism holds true for bad legal arguments which rely on the opinions of ethical experts and argue for judicial change in existing law without reference to established policy protecting the disabled. In this writer's judgment, Father McCormick comes perilously close to violating his own strictures against begging the question and missing the point when he argues, among other things, that "it's very, very misleading language to face into these problems in terms of nondiscrimination on the basis of handicap" because "[t]he question is not whether quality of life ingredients play a part, but where we draw the line." UNITED STATES COMMISSION ON CIVIL RIGHTS, TRANSCRIPT OF HEARING, PROTECTION OF HANDICAPPED NEWBORNS 162 (June 13, 1985) (preliminary print). The point is that Congress has already drawn the line by enacting both Section 504 and the Child Abuse Prevention and Treatment Act, 42 U.S.C.A. § 5102(3) (West Supp. 1985), which set forth very clearly its view that treatment "other than appropriate nutrition, hydration, or medication" must be provided in all cases except those where the child is chronically and irreversibly comatose, the treatment would be futile in terms of survival due to its limited effectiveness, or inhumane. 42 U.S.C.A. § 5102(3) (A-C) (West Supp. 1985). Father McCormick apparently disagrees with this formulation; for he would apparently authorize non-treatment of an infant afflicted with Tay-Sachs Disease and a treatable, unrelated condition which threatens immediate death, such as duode-

American constitutional system and the Equal Protection principle itself.⁹³

nal atresia. See United States Commission on Civil Rights, *supra* at 143-44. Quoted in full, Father McCormick's response to the hypothetical question was as follows:

COMMISSIONER MARY FRANCES BERRY. Father McCormick didn't get to answer that question. Let him answer it first.

FR. McCORMICK. I'd be happy to let it go by if you want me to, but if you want my opinion on that, I think it agrees more closely with Dr. Warren's statement. I think we have here a gray area case where it could go either way. One could bring up a persuasive reason on either side.

I do incline, however, to Dr. Fletcher's cautions that if you did want to suggest treatment, you might be doing it largely in terms of drawing a line so you wouldn't get into further abuses in other instances. But if you isolate the case on its own, you could make a case either way.

Indeed, the most recent authoritative study on this matter by Robert Weir puts Tay-Sachs in the case of withholding or withdrawing treatment.

Id. at 144.

The comments of Dr. Mary Ann Warren and Dr. John Fletcher to which he refers are as follows:

DR. WARREN. I believe that the hypothetical case you describe, a Tay-Sachs child who also has a condition which threatens to cause immediate death, is a case which falls within the gray area, and it could be rationally argued that the treatment should be performed or that it should not. And therefore, this is the sort of case in which a decision should be made primarily by the parents with the best medical counsel and with the help of whatever other counselors they may wish to avail themselves of.

Id.

DR. FLETCHER. If I were asked for an opinion in the case, I would recommend that surgery be done because the Tay-Sachs child will have several months of almost normal life, that is, could live a few months before he or she begins to decline and eventually die by 3 or 4 years old. I think you're correct about the age.

The reasoning I would use for that is that there are too many other cases where you could use the same reasoning in order to justify ending the life of a newborn with a similar degree of handicap by avoiding surgery.

So if you're asking me to comment on that hypothetical case, I could not recommend passivity.

Id.

93. See *United States v. University Hosp.*, 729 F.2d. 144, 163 (2d Cir. 1984) (Winter, J., dissenting) ("A judicial failure to follow the analogy [to race discrimination in cases arising under the laws protecting the handicapped] where it leads is an outright disagreement with Congress' judgment and an unconstitutional act in itself."). See generally sources cited *supra* notes 79, 92 and *infra* note 251.

This point should be distinguished from arguments which rely on federalism to urge that Congress should not interfere with parental or medical judgments concerning the disposition of disabled infants. See, e.g., Brief Amicus Curiae of George P. Smith II at 15-21, *Heckler v. American Hosp. Ass'n*, cert. granted, 105 S. Ct. 3475 (1985). Such arguments neglect not only the authority of Congress to condition receipt of federal funds on adherence to the requirements of Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1982), and the Federal Child Abuse Prevention and Treatment Act, 42 U.S.C. §§ 5101-02 (1982), but also the fact that it was the state courts themselves which approved the denial of necessary treatment notwithstanding state laws prohibiting medical neglect. See, e.g., *Infant Doe v. Bloomington Hosp.*, *supra* note 11. More importantly, they beg the question. See *supra* note 92 and *infra* text accompanying notes 244-51.

It does so by granting the judiciary an immense power: the power to alter fundamental legal notions of the "proper" treatment of the helpless, the aged, and the mentally or physically disabled⁹⁴ by redefining the most fundamental legal right of all — the right to legal protection for one's own life,⁹⁵ and by permitting judges to make the ultimate determination of who shall be counted by the law as having the rights of a human person in the first place.⁹⁶

A. The Problem of Definition

There are few places in the law where the convergence of ethical and legal argument are so intertwined as in the realm of bioethics,⁹⁷ and even fewer which so often merge the divergent goals of common law and constitutional law forms of judicial review.⁹⁸ One need only survey a sampling of recent

94. *City of Cleburne, Texas v. Cleburne Living Center, Inc.*, 105 S. Ct. 3249, 3255-60 (1985). See generally *supra* notes 33-38 and accompanying text.

95. See *Furman v. Georgia*, 408 U.S. 238, 272 (1972) (Brennan, J., concurring) (the right to life is the "right to have rights").

96. *Roe v. Wade*, 410 U.S. 113 (1973), makes it clear that having the status of "person" is essential if the state is to exercise its power and duty to protect the individual's life, liberty or property. *Id.* at 156-58 (noting that were the unborn to be considered persons within the meaning of the fourteenth amendment the asserted right to privacy on which the Court relied to rest the right to abortion would "collapse"). See *In re Yamashita*, 327 U.S. 1, 25 (1946) in which the Court refused to consider the argument that the Nuremberg War Crimes Tribunal had violated Yamashita's rights as a "person" to due process. In dissent, Justice Rutledge noted the dangers of restricting the coverage of the term:

I am completely unable to accept or to understand the Court's ruling [on this issue]. Not heretofore has it been held that any human being is beyond its universally protecting spread That door is dangerous to open. I will have no part in opening it. For once it is ajar, even for enemy belligerents, it can be pushed back wider for others, perhaps ultimately for all.

Id. at 78-79. See also *Santa Clara County v. Southern Pacific Railroad Co.*, 118 U.S. 394, 396 (1886) (holding, without argument, that a corporation is a "person" under the fourteenth amendment); *Boyd v. United States*, 116 U.S. 616, 635 (1885) ("Constitutional provisions for the security of person and property should be liberally construed.").

97. Two others, both relevant to the present discussion, are family law and religious freedom questions. See generally Destro, *The Family and Public Policy* in THE POPE JOHN XXIII MEDICAL-MORAL RESEARCH AND EDUCATION CENTER, THE FAMILY TODAY AND TOMORROW 113-29 (1985). [hereinafter cited as *The Family and Public Policy*].

98. Common law judicial review is aimed at adapting specific judge-made legal principles for which there are no legislative rules to apply to new, but similar, fact-patterns. See generally Calabresi, *supra* note 79, at 90-145. Such changes are subject to immediate revision of the judicial approach through legislative policy-making. Constitutional forms of judicial review, however, are different: their aim is to restrict the unconstitutional exercise of power, not to revise laws thought to be outdated or out-of-step with contemporary needs. The difficulty, of course, is the contemporary problem of "expanding" notions of constitutional rights, and the impact they inevitably will have on legislative determinations with respect to the proper priorities of public policy. See *supra* note 79. Compare sources cited *infra* notes 139, 141, 249 with *Heckman v. Group Health Plan, Inc.*, No. 84-15376 (4th Dist., Hennepin Cty., Minn. August

literature on the topic to appreciate that the process is a dynamic one driven by advances in medical technology and developments in ethics which urge a more open, judgment-oriented approach.⁹⁹ Nonetheless, far too little attention has been paid to the process by which the law is opened to such change.¹⁰⁰ The immediate need to resolve bioethical/legal controversies expeditiously often diverts attention from the nature of the legal process and the significant impact that the process of incremental modification — brought about by a modified “case-by-case” approach which relies on *stare decisis*¹⁰¹ — has on the vitality of basic legal principles.¹⁰²

Once again, the proper place to begin this discussion of the method by which gradual modification of constitutional principle is accomplished is section one of the fourteenth amendment to the Constitution of the United States.¹⁰³ The relevant provision in this context is the Due Process Clause: “nor shall any State deprive any person of life, liberty, or property, without due process of law”, for it governs attempts by the states¹⁰⁴ to limit or otherwise restrict the rights of “any person” to “life, liberty or property”. The operative legal terms are “any person”, “life” and “liberty”. The most effective means for gradually eroding the ethic protected by their original mean-

15, 1985) (order granting summary judgment) (holding that Minnesota's statutory ban on “wrongful birth” cases, MINN. STAT. § 145.424 (1984) is unconstitutional under *Roe v. Wade*, 410 U.S. 113 (1973)).

99. See generally DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT *supra* note 8.

100. See sources cited *supra* note 79.

101. Much has been said in this regard concerning the desirability of a “case-by-case” approach. Given that each case has a unique set of facts, such an approach is to be commended. The cases which are discussed in this essay, however, do not fit the “case-by-case” model; rather they are best described as adopting a “modified” case-by-case approach.

In a true “case-by-case” approach each case would rest on its own footing and would refer directly to the basic constitutional and ethical principles which govern such cases, not to the principles of prior cases involving similar facts. Prior cases would be useful as a guide, but would not compel a given result. This is the preferred approach in constitutional law and is the basis of Justice Powell's statement in *Akron v. Akron Center for Reproductive Health*, 462 U.S. 416 (1983), that *stare decisis* is problematic when the issue is one of constitutional interpretation. *Id.* at 420 n.1.

102. Whether the process is described as a “slippery slope” or in some other fashion which conveys the concept of a gradual disintegration of a concept or value once clear in the law is not particularly important. It is the *process* and its inevitable results which concern me here. For an illustration of this process as it relates to the expansion of the legal definition of “family” see Destro, *supra* note 97, at 116 & n.16. An example in the context of bioethics is contained in the discussion of the rights of a live “fetus *ex utero*” (a premature infant) born after abortion and fetal experimentation. See sources cited *supra* note 74.

103. U.S. CONST. amend. XIV, § 1.

104. The federal government is bound by the strictures of the Due Process Clause of the fifth amendment, which have been interpreted as imposing virtually identical substantive prohibitions on the power of government at the state and federal levels. See, e.g., *Frontiero v. Richardson*, 411 U.S. 677 (1973).

ing has been to obtain their re-definition. The terms remain the same, but their substance reflects the "new" ethic rather than the original one.¹⁰⁵

Analysis of recently decided or currently pending cases involving handicapped newborns and incompetent adults shows that the gradual acceptance of "quality-of-life" reasoning by the judiciary follows precisely this pattern. The constitutional and common law analysis employed by many of these courts is one which is clearly sympathetic to the application of quality-of-life standards, but it is insufficiently brave to state simply that the incompetent subject is just not fit to live.¹⁰⁶ Thus, advocates for a quality-of-life approach content themselves with legal arguments having little (on the surface) to do with the new ethic, and courts, which are required to decide only the cases before them,¹⁰⁷ decide them on those grounds.¹⁰⁸

The quality-of-life arguments made in these cases generally turn on either of two possible legal approaches: judicial expansion of the "liberty" (self-

105. See *infra* text accompanying notes 124-39.

106. See *infra* notes 111-20, 165-98, 239-49 and accompanying text.

107. See generally W. LOCKHART, Y. KAMISAR & J. CHOPER, CONSTITUTIONAL LAW 1625-1705 (5th ed. 1980). Rules governing state court authority to issue advisory opinions differ from state to state.

108. A good example of this tendency in another context is *Eisenstadt v. Baird*, 405 U.S. 438 (1972), in which opponents of laws restricting the ability of unmarried persons to obtain birth control devices argued that "equal protection of the laws" forbade differential treatment of married and unmarried persons. Equality was the asserted rationale used by the Court to negate important legal distinctions between those who are married and those who are not, notwithstanding the fact that the two classes of individuals are not similarly situated for legal purposes, but the true rationale for the decision was judicial disapproval of the substantive legislative policy which restricted the access of unmarried persons to birth control devices or services. Although that substantive legislative judgment may be unwise or incorrect as a matter of public policy, the judicial rationale which invalidated it had little to do with "equality".

That such judicial disingenuity has ramifications in future cases was illustrated during the current term of the United States Supreme Court. In a brief criticizing the Solicitor General Charles Fried's citation of *Eisenstadt* as an "equal protection" case, Professor Laurence Tribe of the Harvard Law School has written: "Virtually every commentator on the case, including the very authors the Government cites in its brief (citation omitted), has recognized that [*Eisenstadt v. Baird*] cannot be defended in standard "equal protection" terms but rests unavoidably on the premise that there exists a special freedom to obtain and use contraceptives—a freedom that goes beyond the marital relationship and the privacy of the home." Brief Amicus Curiae of Senator Bob Packwood, *et al.*, *Thornburgh v. American College of Obstetricians and Gynecologists*, 737 F.2d 283 (3d Cir. 1984), *juris. postponed*, 105 S. Ct. 2015 (1985). Professor Tribe's comments underscore the point made here: that an open-ended "ethic" or "principle" will permit the judiciary to define substantive disagreements with legislative will in whatever fashion is necessary to give them an asserted justification for striking the pre-existing policy in favor of the alternative they prefer. Once the original policy has been gutted, it is then apparently considered to be bad form to take the Court's words concerning the governing principle at face value. The lesson, of course, is that the true importance of a case does not rest upon what the Court says it is doing, but upon an analysis of the legal justification, if any, for what it did.

determination) interest protected by the Due Process Clause and the common law; or limitation of the class of persons covered by presently existing law governing the right of the disabled and handicapped to equal treatment.¹⁰⁹ In either case the foreseeable and intended result is the same: the class of "persons" protected by the law is defined functionally — by what an individual can *do* or *feel*, rather than by reference to their nature: that is, what they *are*.¹¹⁰

When the rationale in such cases is non-constitutional or a mixture of common-law and constitutional analysis, as is often the case where an incompetent adult is the subject of the proceeding, the touchstone is a form of individual liberty which is said to be exercised by proxy.¹¹¹ In cases where the subject is a seriously ill or handicapped child or infant, however, an individual liberty or "self-determination" rationale would be far too transparent a fiction for most courts. In these cases, a quality-of-life ethic is simply infused into the traditional standard in juvenile medical neglect cases, "the best interests of the child,"¹¹² and the means for implementing it is virtually identical to that employed in the case of abortion: a liberty-based "pri-

109. See *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984), *cert. granted sub nom. Heckler v. American Hosp. Ass'n*, 53 U.S.L.W. 3881 (U.S. 1985) (No. 84-1529) (restrictive interpretation of existing law); *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D.D.C. 1983) (same, with additional reliance on "privacy" concerns); *Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985) (common law self-determination, power of the state as *parens patriae* for incompetents).

110. See, e.g., *Roe v. Wade*, 410 U.S. 113, 163 (1973) (concept of "meaningful" life). See also sources cited *infra* notes 166, 182.

111. See, e.g., *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985). The reliance placed on third party "exercise" of the *patient's* rights is a fiction when there is no convincing evidence of the patient's desires, a fact recognized in the *Conroy* dissent. See *id.* at 389, 486 A.2d at 1246 (Handler, J., dissenting). The real issue in "food and water" cases such as *Conroy* is whether death by dehydration or starvation may be authorized by a surrogate. In *Conroy*, the New Jersey court answered the question in the affirmative. The fallacy of this reasoning, however, is that in the rare instance when a competent individual sought judicial acquiescence in their own death by the same means, permission was *denied*. In *Re Caulk*, 125 N.H. 226, 480 A.2d 93 (1984); *California Court Rebuffs Appeal of Quadraplegic*, N.Y. Times, Dec. 28, 1983, at A16, col. 6 (late city ed.). In one recent case, however, a California Appeals Court upheld Elizabeth Bouvia's right not to be force-fed by a nasogastric tube. N.Y. Times, Apr. 20, 1986, A26, col. 1. The hospital intends to appeal the decision. *Id.*

Thus the real purpose of the decision is to allow the surrogate—or the state as *parens patriae*—to make an independent judgment on behalf of the incompetent that his or her life is no longer worth supporting. See 7A ARK. STAT. ANN. § 82-3803 (Supp. 1985) (permitting majority vote of children for a parent and third-party execution of "living will" permitting withdrawal of treatment for a minor or incompetent).

112. CAL. PENAL CODE § 11165 (West 1980); COLO. REV. STAT. § 18-6-401 (1978); D.C. CODE ANN. § 6-2101 (1981); MINN. STAT. ANN. § 626.556 (West 1982); N.Y. SOC. SERV. LAW § 412 (McKinney 1983).

vacy" right of the parents¹¹³ to make whatever medical decisions they consider to be in the "best interests" of themselves and their child.¹¹⁴ And this is so even where the decision is based on an explicit statement that the child "would be better off dead."¹¹⁵

113. Compare, e.g., Fletcher, *Fetal Research: An Ethical Appraisal* in NATIONAL COMMISSION FOR THE PROTECTION OF HUMAN SUBJECTS OF BIOMEDICAL AND BEHAVIORAL RESEARCH, RESEARCH ON THE FETUS: APPENDIX 3-13 (1976).

114. An extended discussion of the scope of parental rights to determine the nature and extent of treatment when a minor child is alleged to be in need of medical care is beyond the scope of this essay, but the topic should be noted in passing due to the reliance of courts and commentators on an asserted parental "privacy" right to be free of government intervention in cases involving difficult medical care decisions. Examination of the cases demonstrates that the courts will not hesitate to intervene in family affairs whenever they determine that a child is in need of treatment, even in the face of a parental claim that they have a constitutional right to refuse treatment. See, e.g., Matter in Appeal In Cochise County, 133 Ariz. 157, 650 P.2d 459 (1982) (en banc); People in the Interest of D.L.E., 200 Colo. 244, 614 P.2d 873 (Colo. 1980) (en banc) (D.L.E. I); People in the Interest of D.L.E., 645 P.2d 271 (1982) (en banc) (D.L.E. II) (same case, one year later); Wallace v. Labrenz, 411 Ill. 618, 104 N.E.2d 769 (1952) (religious objections); Muhlenberg Hosp. v. Patterson, 128 N.J. Super. 498, 320 A.2d 518 (1974) (same); *In re Sampson*, 65 Misc. 2d 865, 317 N.Y.S.2d 641 (Fam. Ct. 1970), *aff'd*, 37 A.D.2d 668, 323 N.Y.S.2d 253 (App. Div. 1971), *aff'd*, 328 N.Y.S.2d 686 (1972) (same). Since the issue is framed as one involving alleged parental neglect, sincere parental concern and affection for the child are not controlling. *State v. Perricone*, 37 N.J. 463, 470, 181 A.2d 751, 759 (1962). Some of the major factors to be considered are: the effect of non-treatment either on the child's chance for life or on his emotional or psychological well-being; the benefits to be derived from the proposed treatment; the risks and potential side effects of proposed treatment plans; medical testimony as to the propriety of the proposed course of action; the child's preference where available; the effect of a delay in implementation of a proposed course of action; and whether or not an emergency exists or whether there is an imminent danger to the child's life. *Id.* at 476, 181 A.2d at 754; Wallace v. Labrenz, 411 Ill. 618, 622, 104 N.E.2d 769, 773 (1952); *In re Hofbauer*, 411 N.Y.S.2d 416, 419 (1978), *aff'd*, 419 N.Y.S.2d 936 (1979); *Custody of a Minor*, 378 Mass. 732, 393 N.E.2d 836, 844 (1979) (*Custody II*); *In re Green*, 448 Pa. 338, 292 A.2d 387, 392 (1972). See *In re Sampson*, 65 Misc. 2d 568, 317 N.Y.S.2d 641 (Fam. Ct. 1970), *aff'd*, 37 A.D. 668, 323 N.Y.S.2d 253 (App. Div. 1971), *aff'd*, 278 N.E.2d 918, 328 N.Y.S.2d 686 (1972). See also, e.g., Comment, *The Outer Limits of Parental Autonomy: Withholding Medical Treatment from Children*, 42 OHIO ST. L.J. 813 (1981); Comment, *The Right to Refuse Medical Treatment: Under What Circumstances Does It Exist?*, 18 DUQ. L. REV. 607 (1980); Comment, *Developments in the Law: The Constitution and the Family*, 93 HARV. L. REV. 1156 (1980). Recent case law indicates that in certain instances the parents may have no rights at all if the court deems it necessary to exclude them altogether from the decision-making process. *City of Akron v. Akron Center for Reproductive Health*, 462 U.S. 416 (1983) (invalidating statute granting parents notice prior to judicial authorization of abortion on an immature minor). It is, therefore, rather anomalous for courts and commentators to rely on an asserted parental right to privacy to refuse medical treatment when the child is handicapped. See, e.g., *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 400 (D.D.C. 1983); Brief Amicus Curiae of George P. Smith, II at 21-26, *Heckler v. American Hosp. Ass'n*, (unreported) (2d Cir. 1984), *cert. granted*, 105 S. Ct. 3475 (1985). To do so is to confuse what the law is (i.e., courts will intervene as a matter of course with what such advocates think it should be or that parents should have unfettered discretion when the child is disabled).

115. Destro & Moeller, *Necessary Care for the Retarded Child: The Case of Phillip Becker*,

The result is that a handicapped infant will not be considered to be fully human until his parents accept him as such¹¹⁶ or until the state demonstrates that the child will be functional.¹¹⁷ Until that time, the child has no rights of its own which are independently enforceable by the state,¹¹⁸ even those which are expressly designed to protect his or her rights as a handicapped person.¹¹⁹ In the case of incompetent adults, the assumption appears to be that they have lost the functional qualities which make them "human." If they, or a "reasonable person" in their situation, would prefer death to their present state of health or incompetence, it is argued that society has no further duty to protect them from legal harm.¹²⁰

B. The Concept of Functional Definition: What is a "Person" for Legal Purposes?

There are two possible ways to define the legally operative term "person": first, by reference to the inherent human nature of the individual (i.e., based on the genetic complement which distinguishes humans from other animals); or second, by reference to qualities the law considers to be necessary for legal

4 HUM. LIFE REV. 81 (1980) [quoting Transcript of Record]; *In re Phillip B., A Minor*, No. 66103 (Super. Ct., Santa Clara County, Cal. Apr. 27, 1978), *aff'd*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 749 (1980).

116. *Cf. Roe v. Wade*, 410 U.S. 113 (1973).

117. *See cases cited infra* at note 119. *See generally* UNITED STATES COMMISSION ON CIVIL RIGHTS, TRANSCRIPT OF HEARINGS, PROTECTION OF HANDICAPPED NEWBORNS (June 12-13, 1985).

118. *See* notes 141-50 and accompanying text.

119. *See supra* text accompanying notes 18-68 and *infra* text accompanying notes 199-233. This issue is raised most clearly in *American Hosp. Ass'n v. Heckler*, No. — (2d Cir. 1984, unreported), *aff'g*, 585 F. Supp. 541 (S.D.N.Y. 1984) relying on *United States v. University Hosp.*, 729 F.2d 144 (2d Cir. 1984), *aff'g*, 575 F. Supp. 607 (N.D.N.Y. 1984)), which held, over the objection of the federal government, that section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1982), had no application to treatment decisions made on behalf of handicapped newborns, and that the Secretary of the Department of Health and Human Services had no authority to issue regulations which would apply Section 504 in this manner. The Supreme Court has granted *certiorari* in *American Hosp. Ass'n* and will decide the applicability of Section 504 to handicapped newborns during the Fall, 1985 Term. *Heckler v. American Hosp. Ass'n* (unreported) (2d Cir. 1984), *cert. granted*, 105 S. Ct. 3475 (1985). In June, 1985 the United States Commission on Civil Rights held hearings into the application of section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1982), to handicapped newborns, and its report and the transcript of its hearings should be published before the end of 1986. *See supra* notes 11, 92. *See also* Child Abuse Amendments of 1984, 42 U.S.C. § 5102 (1984).

120. *Accord* DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 8, at 136. The critical point is that the incompetent patient is not dead, but in a "vegetative" state. *See infra* note 244 and accompanying text. The issue, therefore, is not simply whether the individual should be permitted to die as a result of disease or disability, but whether the existence or extent of disease or disability is sufficient to justify active steps which are intended to cause death—such as withdrawal of food or fluids—and which would not be tolerated in other cases. *See supra* note 84 and *infra* text accompanying notes 164, 244.

protection of an individual personality (i.e., based on those qualities which are alleged to be unique to human function and which are valued in the community). The first approach is unquestionably the basis of a natural rights/"sanctity-of-life" ethic; the second is the basis of a quality-of-life approach.¹²¹

Under a natural rights approach, one need only be genetically human to be entitled to the equal protection afforded all "persons" by the law. Such a standard does not rest on the assent of the state; for the state is not the power which confers either the human nature or the "unalienable rights" which come with it.¹²² The duty of the state and others is to respect and to protect those rights against all who would violate them without due process of law.¹²³ As Thomas Jefferson put it in 1809, "[t]he care of human life and happiness, and not their destruction, is the first and only legitimate object of good government."¹²⁴

This view finds expression in the natural rights language of the American Declaration of Independence, which states the belief of its authors that the ethic which holds "that all men are created equal and that they are endowed by their Creator with certain unalienable rights" is "self-evident" truth.¹²⁵ The exhortations of John Bingham, the author of section one of the fourteenth amendment, also reflect the natural rights ethic. His view, declared on the floor of the United States House of Representatives during the 1867 debates over the fourteenth amendment, was that "the only question to be asked of the creature claiming [the amendment's] protection is this: Is he a man?"¹²⁶

The view that an individual should not be considered to be a person unless it can be demonstrated to the satisfaction of the state that he or she is functionally human is best summarized by the the views of the Austrian scholar

121. *Accord* DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT *see supra* note 8, at 135 n.43.

[The phrase] quality-of-life has been used in differing ways; sometimes it refers to the value that the continuation of life has for the patient, and other times to the value that others find in the continuation of the patient's life, perhaps in terms of their estimates of the patient's actual or potential productivity or social contribution. . . .

122. *Loan Ass'n v. Topeka*, 87 U.S. (20 Wall.) 655, 662 (1875):

It must be conceded that there are such rights in every free government beyond the control of the State. A government which recognized no such rights, which held the lives, the liberty, and the property of its citizens subject at all times to the absolute disposition and unlimited control of even the most democratic depository of power, is after all but a despotism.

123. *See generally* R. BERGER, *GOVERNMENT BY JUDICIARY* 166-248 (1978).

124. Speech to the Republican Citizens of Washington County, Maryland (March 31, 1809), *reprinted in* J. BARTLETT, *FAMILIAR QUOTATIONS*, 472-73 (14th ed. 1968).

125. The Declaration of Independence para. 2 (U.S. 1776).

126. Cong. Globe, 40th Cong., 1st Sess. 542 (1867).

Hans Kelsen. Professor John Noonan has described Kelsen's jurisprudential views on the issue as follows:

In Kelsen's view, the legal order is the source of all legal rights, and a 'person' is merely the personification of such legal rights. In his words, 'The physical (natural) person is, thus, no natural reality but a construction of juristic thinking.' If the legal order does not recognize any rights in a human being, such a human being is not a person.¹²⁷

Kelsen's view of the functional nature of the human person also finds support in American law. Perhaps the best example of such reasoning is that which motivated the American South's "peculiar institution": Slavery. Chief Justice Roger Taney's words for the Supreme Court in *Dred Scott v. Sanford*¹²⁸ are the essence of an ethic which exalts function over nature in order to determine who shall have rights:

They [persons of Black African descent] had for more than a century before been regarded as beings of an inferior order; and altogether unfit to associate with the white race, either in social or political relations; and so far inferior, that they had no rights which the white man was bound to respect; and that the negro might justly and lawfully be reduced to slavery for his benefit. He was bought and sold, and treated as an ordinary article of merchandise and traffic, whenever a profit could be made by it. . . . [They] were never thought of or spoken of except as property, and when the claims of the owner or the profit of the trader were supposed to need protection."¹²⁹

By the time the Court decided *Dred Scott*, however, the policy of some states had begun to accept a natural rights ethic. No matter. The use of a functional ethic was, in Taney's view, part and parcel of constitutional adjudication itself. Whatever change in attitude had prompted some states to

127. J. NOONAN JR., A PRIVATE CHOICE 13-14 (1979) (quoting F. Kelsen, THE PURE THEORY OF LAW 94-95 (M. Knight trans. 2d ed. 1967)).

The New York Court of Appeals adopted Kelsen's line of reasoning in *Byrn v. New York City Health & Hosps. Corp.*, 31 N.Y.2d 194, 200-01, 286 N.E.2d 887, 889, 335 N.Y.S.2d 390-91 (1972):

What is a legal person is for the law . . . to say, which simply means that upon according legal personality to a thing the law affords it the rights and privileges of a legal person That the legislative action may be wise or unwise, even unjust and violative of principles beyond the law, does not change the legal issue or how it is to be resolved. The point is that it is a policy determination whether legal personality should attach and not a question of biological or "natural" correspondence.

But see *Glon v. American Guarantee Co.*, 391 U.S. 73, 75-76 (1968) (rejecting the "legal" - "biological" distinction).

128. 60 U.S. (19 How.) 393 (1857).

129. *Id.* at 407, 410.

disallow slavery, he wrote, had nothing to do with the human nature of Blacks: the reason for legal change was purely functional. "[I]t was discovered, from experience," wrote the Chief Justice, "that slave labor was unsuited to the climate and productions of these States."¹³⁰

Even though the debates over section one of the fourteenth amendment,¹³¹ including the impassioned speeches of its author,¹³² should make it abundantly clear that the amendment is based on a natural rights view of the inherent worth of the human person, the Supreme Court has not hesitated to write its own quality-of-life/functional ethic into the cases whenever its own prejudices seemed to call for it. In *Buck v. Bell*,¹³³ for example, the Supreme Court held that a woman committed to a state mental institution may be sterilized to prevent her bearing retarded children. The functional approach of a quality-of-life rationale is explicit.

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could

130. *Id.* at 412.

131. For a discussion of the history of the fourteenth amendment as it relates to the obligation of government to protect the lives of individuals see *The Need for a Life-Protective Amendment*, *supra* note 7, at 1288-90 & nn.190-209.

132. See, e.g., Address by Congressman John A. Bingham, Bowerstown, Ohio, August 24, 1866, printed in *Cincinnati Commercial*, August 27, 1866, at 1, col. 3:

[The amendment] imposes a limitation upon the States to correct their abuses of power, . . . Look at that simple proposition. No State shall deny to any person, no matter whence he comes, or how poor, how weak, how simple — how friendless — no State shall deny to any person within its jurisdiction the equal protection of the laws. . . . That proposition, I think, my fellow citizens, needs no argument. No man can look his fellow-man in the face, surrounded by this clear light of heaven in which we live and dare to utter the proposition that of right any State in the Union should deny to any human being who behaves himself well the equal protection of the laws. Paralysis ought to strangle the tongue before a man should be guilty of the blasphemy that he himself to the exclusion of his fellow man, should enjoy the protection of the laws.

Accord remarks of Congressman John A. Bingham, House of Representatives, Cong. Globe, 39th Cong., 1st Sess. 1089 (1866):

If a State has not the right to deny equal protection to every human being under the Constitution of this country in the rights of life, liberty, and property, how can State rights be impaired by penal prohibitions of such denial as proposed?

For a present-day argument that federalism concerns should lead the Supreme Court to permit the states to utilize quality-of-life approaches in their construction of child-neglect statutes, see Brief Amicus Curiae of George P. Smith II, *Heckler v. American Hosp. Ass'n* (unreported) (2d Cir. 1984), *cert. granted*, 105 S. Ct. 3475 (1985), arguing that federalism and parental rights can be cited as a possible rationale for rejecting federal protection for handicapped infants. For a review of the remarks of other sponsors of the fourteenth amendment, including the Senate floor leader, Senator Jacob M. Howard, and Representatives Thaddeus Stevens and Edgar Cowan, see *The Need for a Life-Protective Amendment*, *supra* note 7, at 1332 & nn.399-400.

133. 274 U.S. 200 (1927).

not call upon those who already sap the strength of the State for these lesser sacrifices, often not felt to be such by those concerned, in order to prevent our being swamped with incompetence. It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. . . . Three generations of imbeciles are enough.¹³⁴

Justice Holmes' position in *Buck v. Bell* is relevant to the present inquiry for both its explicit adoption of a functional approach to questions of entitlement to basic human rights, and its implicit assumptions about the role of government in the process. Notably, it has never been overruled.¹³⁵ It assumes, among other things, 1) that certain individuals may be described as "manifestly unfit"; 2) that government may decide when individuals are in accordance with a quality-of-life formula; 3) that those who are "manifestly unfit" because of a disability do not have the same rights to equal protection under law as others; and 4) that the result consistent with the quality-of-life formulation is "best" for all the world, even though "not often felt to be such by those [who are declared to be unfit and who are immediately] concerned." Careful examination of cases adopting a functional approach reveals that each one rests on some formulation of the same elements, and each, in its own way, reaches the same result.

The most recent explicit acceptance of a functional ethic of human rights by the Supreme Court came in *Roe v. Wade*.¹³⁶ In *Roe*, the Court espoused the view that the unborn offspring of human parents, a human fetus, must be capable of "meaningful life"¹³⁷ outside the womb before he or she can be considered as having anything more than the "potential" for human life.¹³⁸ Genetic identity is, under this formulation, irrelevant, except to determine "potential" for human life. But this "potential", standing alone, is, in the Court's view, insufficient to permit legal recognition of the unborn

134. *Id.* at 203.

135. The late Justice William O. Douglas cited *Buck v. Bell* with approval in support of his position that the state has power to protect its interests against "hereditary forms of insanity or imbecility" in *Doe v. Bolton*, 410 U.S. 179, 215 (1973) (Douglas, J., concurring). In *Skinner v. Oklahoma*, 316 U.S. 535 (1942), the Court explicitly validated the eugenic rationale of *Buck v. Bell* when it found that the statute was invalid because, unlike the one in *Bell*, it gave "the defendant no opportunity to be heard on the issue as to whether he is the probable parent of socially undesirable offspring." *Id.* at 538. Justice Stone's concurring opinion makes it clear that the "Court has sustained such an experiment [sterilization] with respect to an imbecile, a person with a definite and observable characteristic, where the condition had persisted through three generations and afforded grounds for the belief that it was transmissible and would continue to manifest itself in generations to come." *Id.* at 546.

136. 410 U.S. 113 (1973).

137. *Id.* at 163.

138. *Id.* at 150, 164-65.

offspring of human parents as a "person" under the fourteenth amendment. More — "meaningful life" — is required.

Since *Roe*, the development of this "meaningful life" standard has developed in logical progression as hard case follows and builds upon hard case, each raising different permutations of the same question: when does a life which is genetically human have "meaning" for its own sake (intrinsic meaning) and for others (extrinsic meaning)? In this fashion the quality-of-life ethic which holds that "lives without meaning" are without value under the law has expanded to the point where courts have held that the birth of a handicapped child can support a damage claim against a physician,¹³⁹ and that prenatal eugenic selection of children is a matter of constitutional right which cannot be infringed by either the physician or the state.¹⁴⁰ One court has even gone so far as to hold that a parent who takes no action to prevent the birth of a child with incurable handicaps might be liable to the child under a theory of "wrongful life",¹⁴¹ apparently because it would be condemned to a life "without meaning". And so the law based on the functional ethic expands, driven inexorably by the press of new cases and the *stare decisis* effect of the first principles and ethics upon which it is based.¹⁴²

C. *Accepting the Functional Definition: Recent Case Law Involving Handicapped Infants and the Elderly*

That precisely this sort of quality-of-life reasoning is gaining acceptance in

139. In a wrongful birth action the claim is based on the assertion that the physician negligently failed to inform the parents of a significant risk that the child might be born with defects. A closely related theory is "wrongful pregnancy", where it is alleged that the defendant negligently performed a sterilization operation or negligently supplied contraceptives. See cases cited *infra* note 249. See also *Hickman v. Group Health Plan, Inc.*, No. 84-15376 (4th Dist., Hennepin City, Minn. Aug. 15, 1985) (order granting summary judgment). In *Hickman* a Minnesota district court ruled that the state statute which prohibited wrongful birth actions was unconstitutional in that it allegedly interfered with a woman's rights under *Roe v. Wade*, 410 U.S. 113 (1973).

140. *Hickman v. Group Health Plan, Inc.*, No. 84-15376, slip. op. at 13 (4th Dist. Hennepin County, Minn. Aug. 15, 1985).

141. *Curlender v. Bio-Science Laboratories*, 106 (Cal. App. 3d 811, 165 Cal. Rptr. 477 (1980)). A "wrongful life" case is an action brought on behalf of the child for injuries suffered from an alleged negligent failure to prevent its birth. Every jurisdiction which has considered the issue, except for the decision of one intermediate Court of Appeal in California, has held that no such cause of action exists. *e.g.*, *Elliott v. Brown*, 361 So. 2d 546 (Ala. 1978); *Turpin v. Sortini*, 31 Cal. 3d 220, 643 P.2d 954, 182 Cal. Rptr. 337 (1982); *Becker v. Schwartz*, 47 N.Y.2d 401, 386 N.E.2d 807, 413 N.Y.S.2d 895 (1978); *Dumer v. St. Michael's Hosp.*, 69 Wis. 2d 766, 233 N.W.2d 372 (1975); *Jacobs v. Theimer*, 519 S.W.2d 846 (Tex. 1975). *Curlender's* "wrongful life" theory was disapproved by the California Supreme Court in *Turpin v. Sortini*. Its holding that parents might be held liable was negated by amendment of the California Civil Code. CAL. CIV. CODE § 43.6 (West 1982).

142. See *supra* text accompanying note 105.

the law governing the rights of the handicapped and elderly cannot be doubted. In *American Academy of Pediatrics v. Heckler*,¹⁴³ for example, Judge Gerhard Gesell explicitly held that before the United States Department of Health and Human Services could promulgate regulations under Section 504 of the Rehabilitation Act of 1973¹⁴⁴ to protect handicapped newborns from non-treatment decisions which would likely lead to death, it was required to take into account "the quality of the infant's expected life"¹⁴⁵ and the potential for adverse "economic, emotional and marital effects on the family as a whole" due to "the effort to preserve an unwanted child".¹⁴⁶ Notably, the court relied expressly on *Roe v. Wade* for the proposition that parents may have a privacy right to demand that the government refrain from interfering with quality-of-life judgments which may result in the death of their child from lack of treatment or nourishment.¹⁴⁷

Thus begins the two-pronged process of re-defining the pre-existing legal rights of the person whose life is at stake: in this case, a handicapped newborn child.¹⁴⁸ The starting point is the acceptance of the functional ethic in

143. 561 F. Supp. 395 (D.D.C. 1983).

144. 29 U.S.C. § 794 (1982). The requirements of Section 504 are discussed at length in Part I, *supra* text accompanying notes 39-68.

145. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 400.

146. *Id.*

147. *Id.* at 403 (dictum).

148. Judge Gesell did not cite any case which held that Section 504 of the Rehabilitation Act of 1973, 29 U.S.C. § 794 (1982) did not apply to handicapped newborns. Instead, he invalidated the regulations on the ground that the Department of Health and Human Services had acted improperly when it enacted the so-called "Baby Doe" rules as "interim final rules" under the Administrative Procedure Act, 5 U.S.C. §§ 551, 553(b)(d), 706(2)(A) (1982). Nonetheless, it is quite clear that the thrust of his opinion is that Section 504 was not intended to apply to all handicapped newborns, notwithstanding its broad requirement that "[n]o otherwise qualified handicapped individual . . . shall, solely by reason of his handicap, be excused from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." Although the United States Court of Appeals for the Second Circuit felt that Judge Gesell had "reasoned that the interim final rule could not properly be viewed as a restatement of pre-existing law or policy, as the government had alleged," *United States v. University Hosp.*, 729 F.2d 144, 153 (2d Cir. 1984), it is clear from the opinion in *Heckler* that pre-existing law was not given a broad interpretation because of the quality-of-life dimensions of the issues at bar. Judge Gesell wrote:

The legislative history of [Section 504] focuses on discrimination against adults and older children and denial of access to federal programs. As far as can be determined, no congressional committee or member of the House or Senate ever even suggested that section 504 would be used to monitor medical treatment of defective newborn infants or establish standards for preserving a particular quality of life. . . . On the other hand, the statute on its face is open to a broad and all-inclusive interpretation. . . . While the term "infant" in the regulation is not defined, at least *some* infants born with physical and mental defects may well fit within that broad definition.

American Academy of Pediatrics v. Heckler, 561 F. Supp. at 401-02. The import of such reasoning for the future development of the law is clear. In at least one court's opinion, Con-

Roe, and the once-clear dividing line between born and unborn falls to the relentless logic of an expanding first principle that life must have function and meaning in order to warrant legal protection. Thus, the first inquiry is "the quality of the [child's] expected life"¹⁴⁹ and impact that that life will have on others.¹⁵⁰ The second is an inquiry into whether the court should hold that the "competing interests at stake" require a limitation on or exception to the power of government to regulate on the basis of the pre-existing natural rights ethic.¹⁵¹ And, the last is reliance on the claim that the "pri-

gress must speak affirmatively before the quality-of-life ethic preferred by the judiciary can be supplanted by a legislative one which would include all handicapped infants, and even then, the result may well be overridden by the courts' view that the constitutional "right to privacy" includes the right of parents to make medical decisions based on a quality-of-life ethic. This conclusion is buttressed by the overt narrowing of a term in the regulations which, the court points out, is undefined: "infant". Precisely why an explicit definition for such an obvious term would be necessary given its "plain English" meaning — a baby — is unclear. But Judge Gesell provides the answer by limiting the term "infant" to reflect the quality-of-life ethic position that not all persons deserve legal protection: "While the term 'infant' in the regulation is not defined, at least some infants born with physical and mental defects may well fit within that broad definition." *Id.* at 402.

149. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. at 400. The United States Court of Appeals for the Second Circuit took a different view of the intent of the statute with respect to infants, *see United States v. University Hosp.*, 729 F.2d 144, 156-57 (2d Cir. 1984), and held that handicapped infants are indeed "handicapped individuals" under Section 504, but that they are not "otherwise qualified" for treatment when the handicapping condition is one of the alleged causes of the need for treatment. The result, of course, is the same as in *American Academy of Pediatrics v. Heckler*. Even though "the words and purpose of the statute plainly apply to a particular situation," and even though "the fact that the specific application of the statute never occurred to Congress does not bar [the court] from holding that the situation falls within the statute's coverage," *United States v. University Hosp.*, 729 F.2d at 159 (quoting *United States v. Jones*, 607 F.2d 269, 273 (9th Cir. 1979), *cert. denied*, 444 U.S. 1085 (1980)), the Second Circuit refused to apply existing law to protect an infant who was a "handicapped individual" covered by the statute because "the situation in question [here] is different in kind, not just in degree, from the applications of section 504 discussed in the legislative history," and that "Congress . . . must first weigh the competing interests at stake in this context" before the judiciary will allow the Executive Branch to act to apply the plain meaning of the statute." *Id.*, 729 F.2d. at 159-60, 161.

150. 729 F.2d at 161.

151. In his dissent in *United States v. University Hosp.*, 729 F.2d 144, 161 (2d Cir. 1984), Judge Winter pointed out that "Congress was persuaded that a handicapped condition is analogous to race and that, so far as the administration of federal financial assistance is concerned, discrimination on the basis of handicap should be on a statutory par with discrimination on the basis of race." *Id.* at 162. Given the "natural rights" foundation of the constitutional and statutory prohibitions on race discrimination, *see supra* notes 122-31 and accompanying text, such a finding would place the burden on those arguing *against* expansive coverage for the handicapped. The majority in *United States v. University Hosp.*, however, placed the burden *on the government*, which sought to apply the statute in accordance with its broad intention. As Judge Winter pointed out:

A judgment not to perform certain surgery because a person is black is not a *bona fide* medical judgment. So too, a decision not to correct a life threatening digestive problem because an infant has Down's Syndrome is not a *bona fide* medical judg-

vacy"-as-a-function-of-"liberty" rationale of *Roe v. Wade* and its progeny will not allow the law based on a natural rights ethic to function in such situations.¹⁵²

The process is similar, though not identical, in the case of incompetent or

ment. The issue of parental authority is also quickly disposed of. A denial of medical treatment to an infant because the infant is black is not legitimated by parental consent. . . .

Any doubt [in this case] must stem not from a deficiency in the argument based on the analogy to Title VI of the Civil Rights Act but from a disagreement as to whether a handicapped condition is fully analogous to race. See *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 402 (D.D.C. 1983). Whether that doubt is justified or not, however, courts are not the proper fora in which the reasonableness of the analogy to race is to be judged.

United States v. University Hosp., 729 F.2d 144, 162 (2d Cir. 1984) (Winter, J., dissenting).

152. The cases cited by Judge Gesell in *American Academy of Pediatrics v. Heckler*, were *Carey v. Population Servs. Int'l*, 431 U.S. 687, 684-858 (1977); *Roe v. Wade*, 410 U.S. 113, 152-53 (1973); and *Griswold v. Connecticut*, 381 U.S. 479, 484 (1965). While only *Carey* can be considered one of *Roe*'s "progeny", all the cases cited, as well as numerous others which rest upon them, are based on a theory that certain decisions, and access to the means to implement them, are outside the realm of legitimate government intervention, whether or not they are actually "private" in nature. Compare, e.g., *Griswold v. Connecticut*, 381 U.S. 479 at 482, 486 (opinion of the Court), *id.* at 502-03 (White, J., concurring) (relying on the privacy of the marital bedroom and "the intimacies of the marriage relationship"), with, e.g., *Carey v. Population Servs. Int'l* (relying on "privacy" to permit minors access to sale of contraceptives) and *Doe v. Bolton*, 410 U.S. 179 (1973) (relying on "privacy" to strike health regulations governing the medical and business practices of abortion-providers). It is noteworthy that the United States Court of Appeals for the Second Circuit relied, in part, on the same cases to support its conclusion that the Department of Health and Human Services could not rely on Section 504 to support an investigation into allegations of discriminatory refusal of medical care to a handicapped infant. *United States v. University Hosp.*, 729 F.2d 144, 150 (2d Cir. 1984) (citing *Carey*, *Griswold* and *Roe*, among others). At bottom, however, the rationale of these cases is quite clear: the courts simply do not agree with the legislature's judgment concerning the proper outcome. *Roe*, for example, rests explicitly on the notion that the legislature may not adopt "one theory of life" which would interfere with the liberty interests of the pregnant woman. 410 U.S. at 163. The same rationale is employed implicitly when the language and logic of *Roe* is utilized in cases involving disabled infants. See, e.g., *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 400 (D.D.C. 1983) (reference to "the effort to preserve an 'unwanted' child"). It is safe to predict that the courts which prefer the quality-of-life view would find it politically impossible to adopt an explicit statement that the state simply may not interfere with parents who do not wish to raise a retarded or disabled child, so the privacy rationale is a convenient substitute. Other writers, not having the need to defend their views either politically or in higher courts, have taken the direct approach. The most notable of these is the Australian ethicist Peter Singer who wrote:

We can no longer base our ethics on the idea that human beings are a special form of creation, made in the image of God, singled out from all other animals, and alone possessing an immortal soul. Our better understanding of nature has bridged the gulf that was once thought to lie between ourselves and other species, so why should we believe that the mere fact that a being is a member of the species *Homo sapiens* endows its life with some unique, almost infinite, value?

Singer, *supra* note 72, at 129.

seriously ill adults. In the case of adults, the order of inquiry is reversed; with the inquiry into the "privacy"/"liberty" aspects of the case handled first¹⁵³ due to the well-settled common-law right of a competent adult to refuse consent for unwanted medical treatment.¹⁵⁴ From that point, the discussion begins to look much like those involving third-party consent for non-treatment of handicapped infants. The main difference, of course, is that the guardian is said to be exercising the rights of the incompetent adult, rather than his own.¹⁵⁵ Nevertheless, the result is the same: the preservation of an incompetent adult's life depends upon the subjective evaluation of a court and a guardian who will, in many if not most cases, depend either implicitly or explicitly on quality-of-life criteria to determine whether to continue treatment or render it in the first instance.

The New Jersey Supreme Court's recent decision in *In re Conroy*,¹⁵⁶ bears witness to the difficulties of attempting to soften the reality of what is being authorized.¹⁵⁷ Under the "subjective test" articulated in *Conroy*, the courts are encouraged to undertake a search for the previously-expressed desires of the incompetent adult,¹⁵⁸ but it is not at all clear that those desires will always be relevant.¹⁵⁹ Under the other two formulations approved in the case — the "limited objective" and the "pure objective" tests,¹⁶⁰ however,

153. See, e.g., *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985), *rev'g*, 190 N.J. Super. 453, 464 A.2d 303 (App. Div. 1983), *rev'g*, 188 N.J. Super. 523, 457 A.2d 1232 (1983); *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied*, 429 U.S. 922 (1976). In *Conroy*, the New Jersey Supreme Court rejected the privacy rationale it had adopted in *Quinlan* in favor of what it considered to be a more accurate formulation: the concept of self-determination. *Conroy*, 98 N.J. at 348, 486 A.2d at 1223 & n.154.

154. See, e.g., *Schloendorff v. Society of New York Hosp.*, 211 N.Y. 125, 129-30, 105 N.E. 92, 93 (1914) *quoted in In re Conroy*, 98 N.J. 321, 346, 486 A.2d 1209, 1222 (1985). Although a thorough discussion of the common law treatment of unconsented touching, including medical care, as a battery is beyond the scope of this essay, it is relevant to the present discussion to note that the right is not absolute, even for a competent adult. Thus, although the New Jersey Supreme Court stated that "[t]he right of a person to control his own body is a basic societal concept, long recognized in the common law," *In re Conroy*, 98 N.J. at 346, 486 A.2d at 1221, it also expressly recognized that the common-law right to refuse medical care is not absolute and must give way in the face of an important governmental interest. *Id.* at 348-54, 486 A.2d at 1223-26. See also *Jacobson v. Massachusetts*, 197 U.S. 11 (1905); *Application of President & Directors of Georgetown College, Inc.*, 331 F.2d 1000, 1008 (D.C. Cir. 1964), *cert. denied*, 377 U.S. 978 (1964); *In re Caulk*, 125 N.H. 226, 480 A.2d 93, 96-97 (1984); *State v. Perricone*, 37 N.J. 463, 181 A.2d 751, *cert. denied*, 371 U.S. 890 (1962).

155. Compare *In re Conroy*, 98 N.J. 321, 348, 486 A.2d 1209, 1223 (1985) with *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 265, 400-02 (D.D.C. 1983).

156. 98 N.J. 321, 486 A.2d 1209 (1985) *rev'g* 190 N.J. Super. 453, 464 A.2d 303, *rev'g* 188 N.J. Super. 523, 457 A.2d 1232.

157. 98 N.J. at 391, 486 A.2d at 1246 (Handler, J., concurring and dissenting).

158. *Id.* at 360-64, 486 A.2d at 1229-31.

159. *Id.* at 362-63, 486 A.2d at 1230-31. See also sources cited *supra* at note 111.

160. 98 N.J. at 365, 486 A.2d at 1232.

neither the intention of the incompetent patients, nor their right to self-determination can validly be claimed as the basis for decision.

Therefore the New Jersey Supreme Court was correct when it pointed out that, "in the absence of adequate proof of the patient's wishes, it is naive to pretend that the right to self-determination serves as the basis for substituted decision-making".¹⁶¹ The real issue is: what ethic — functional or natural rights — will govern the law of New Jersey when the issue is whether the state should permit termination of a patient's life on the basis of allegations by a guardian or physician that death is in the patient's "best interests":

We hesitate, however, to foreclose the possibility of humane actions, which may involve termination of life-sustaining treatment, for persons who never clearly expressed their desires about life-sustaining treatment but who are now suffering a prolonged and painful death. An incompetent, like a minor child, is a ward of the state, and the state's *parens patriae* power supports the authority of its courts to allow decisions to be made for an incompetent that serve the incompetent's best interests, even if the person's wishes cannot be clearly established. This authority permits the state to authorize guardians to withhold or withdraw life-sustaining treatment from an incompetent patient if it is manifest that such action would further the patient's best interest in a narrow sense of the phrase, even though the subjective test . . . may not be satisfied.¹⁶²

The language just quoted represents the New Jersey Supreme Court's acceptance of the *method* by which the pre-existing rights of the handicapped elderly are placed in jeopardy.¹⁶³ The details are to be worked out in later cases, but the direction is clear. Each of the four assumptions accepted in *Buck v. Bell* have been accepted here: the unfitness of an individual; the power of the state to make quality-of-life judgements for its wards; the potential that the individual might disagree, and the minor role that this potential for disagreement plays in deciding what is in his or her best interests. The assumptions which would be implicit in a natural rights analysis do not even enter the picture because, in the court's view, they might "foreclose the

161. *Id.* at 364-65, 486 A.2d at 1231. See also *id.* at 392-93, 486 A.2d at 1246-47.

162. *Id.* at 364-65, 486 A.2d at 1231. See also *id.* at 392-93, 486 A.2d at 1246-47. (Handler, J., concurring and dissenting) ("What is really involved . . . is not so much the incompetent's right to personal choice — nature has already deprived her of that — but rather what is in her best interests.").

163. It should be noted at this point that the method is identical to that utilized in the case of handicapped infants and neglect cases involving children: reliance on the power of *parens patriae*. A thorough discussion of either the power itself or the means by which it has been used to advance a quality-of-life ethic is beyond the scope of this article. See generally *The Family and Public Policy*, *supra* note 97.

possibility of humane actions" to terminate life¹⁶⁴ in future cases involving incompetents with dim medical prognoses.

But acceptance of a new governing ethic is a big step, and the court implicitly recognized the risk it was taking when it emphasized that New Jersey law "secure[s] for elderly patients, residents and clients of health care facilities serving their specialized needs and problems, the same civil and human rights guaranteed to all citizens."¹⁶⁵ Its explicit rejection of a "broad" quality-of-life formula¹⁶⁶ in favor of a narrower one which focuses largely on the incompetent's susceptibility to pain demonstrates its concern that the new ethic has an expansive logic of its own, and that express limitations are needed:

Although we are condoning a restricted evaluation of the nature of a patient's life in terms of pain, suffering, and possible enjoyment under the limited-objective and pure-objective tests, we expressly decline to authorize decision-making based on assessments of the personal worth or social utility of another's life, or the value of that life to others. We do not believe that it would be appropriate for a court to designate a person with the authority to determine that someone else's life is not worth living simply because, to that person, the patient's "quality-of-life" or value to society seems negligible. The mere fact that a patient's functioning is limited or his

164. The distinction between terminating life itself and terminating life-sustaining treatment is an important one which is discussed in the context of the *Conroy* case. For present purposes, however, it is sufficient to note that the "life-sustaining treatment" was nothing more than food and water provided by a nasogastric tube. It was not, therefore, "treatment" as that term is commonly understood, notwithstanding the New Jersey court's conclusion that the distinction between providing food and water and providing other treatments is more emotional than real. *Conroy*, 98 N.J. at 372-74, 486 A.2d at 1236. This writer rejects that conclusion as being inherently inconsistent with both the rights of patients to treatment and the duty of the family and society to subscribe to the medical ethic which derives from the natural rights formulation of human worth: *primum non nocere* ("first do no harm"). See *infra* Part III. See also *Corbett v. D'Alessandro*, No. 84-5627 CA-JRT (Fla. Cir. Ct. Feb. 28, 1985) (Court held that a nasogastric tube could not be withheld or withdrawn from a person in a permanently vegetative state because a state statute expressly stated that the provision of sustenance was *not* a form of life-prolonging procedure that may be discontinued or withheld).

165. *Conroy*, 98 N.J. at 379, 486 A.2d at 1239 (quoting N.J. STAT. ANN. § 52:27G-1 (1981)).

166. *Id.* at 367, 486 A.2d at 1232-33. See also *In re Dinnerstein*, 6 Mass. App. Ct. 466, 472, 380 N.E.2d 134, 138 (1978) (indicating, in reference to possible resuscitation of half-paralyzed, elderly victim of Alzheimer's disease, that prolongation of life is not required if there is no hope of return to a "normal integrated, functioning, cognitive existence"); DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 8, at 135 (endorsing termination of treatment whenever surrogate decision-maker, in his discretion, believes it is in the patient's best interests, defined broadly to "take into account such factors as the relief of suffering, the preservation or restoration of functioning, and the quality as well as the extent of life sustained").

prognosis dim does not mean that he is not enjoying what remains of his life or that it is in his best interests to die. [citations omitted] More wide-ranging powers to make decisions about other people's lives, in our view, would create an intolerable risk for socially isolated and defenseless people suffering from physical or mental handicaps. . . .

* * *

When evidence of a person's wishes or physical or mental condition is equivocal, it is best to err, if at all, in favor of preserving life.¹⁶⁷

The difficulty with this sort of reasoning is that it contains the seeds of its own demise. The process of evaluating life on the basis of its quality rather than its nature, once accepted, will inexorably lead to extensions of the rationale as the cases get harder, and death appears as the most humane alternative under the circumstances. Justice Handler's dissenting opinion in *Conroy* made the point explicitly when he observed that neither "justice, efficacy, [n]or humaneness . . . would require a person to die", as Claire Conroy did, with a nasogastric tube in place.¹⁶⁸ His preference was for the "best interests" standard approved by the President's Commission.¹⁶⁹

Although Justice Handler's understanding of the "best interests" standard suggested by the President's Commission is somewhat different than the Commission's own definition,¹⁷⁰ he apparently preferred its view because it does "not give determinative weight to the element of personal pain," and because it does not "necessarily obviate other extremely important considerations."¹⁷¹ In his view, the preferred standard "should accommodate as comprehensively, fairly, and realistically as possible all concerns and values that have a legitimate bearing on the decision whether to provide particular treatment at the very end of an individual's life".¹⁷² But a standard which relies on "all concerns and values that have a legitimate bearing on the decision" identified in the President's Commission report is precisely the broad quality-of-life standard the majority in *Conroy* thought it was rejecting.

Although the Commission's report claims that "[i]n applying the best interest principle, [it] is concerned with the value of the patient's life for the

167. *Conroy*, 98 N.J. at 367-68, 486 A.2d at 1232-33.

168. *Id.* at 391, 486 A.2d at 1246.

169. *Id.* at 396-99, 486 A.2d at 1248-49 (quoting DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 8, at 135 (footnote omitted)).

170. Compare *Conroy*, 98 N.J. at 393-99, 486 A.2d at 1246-50 with DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 8, at 134-36 & nn.41-45.

171. *Conroy*, 98 N.J. at 392, 486 A.2d at 1246.

172. *Id.*

patient,"¹⁷³ it also states that the "impact of a decision on an incapacitated patient's loved ones may be taken into account [by the surrogate] in determining someone's best interests, [because] most people do have an important interest in the well-being of their families or close associates."¹⁷⁴ This is not the "best-interests-of-the-patient-as-seen-through-the-eyes-of-the-patient" standard it purports to be. It is a significant extension of the "pure subjective" and "limited objective" tests which would determine "what is in the [patient's] best interests by reference to more objective, societally shared criteria" without reference to the value of self-determination.¹⁷⁵ It is, in fact, a "pure objective" test which expressly recognizes that the value of the patient's life to the patient "is impossible to discern with any certainty,"¹⁷⁶ and which relies instead on the views of "the average, reasonable person in the patient's position"¹⁷⁷ to determine whether or not the patient's life creates "emotional or financial burdens for their family or other people to whom they were close."¹⁷⁸

This is precisely the extension of the functional ethic correctly rejected by the majority in *Conroy*, but accepted in other cases.¹⁷⁹ It has absolutely no place in a "best interests" discussion which purports to rely on "the value of the patient's life for the patient,"¹⁸⁰ rather than others' "estimates of the patient's actual or potential productivity or social contribution,"¹⁸¹ for it introduces precisely the quality-of-life standard it eschews by permitting the well-being of others to be counted as a factor in determinations regarding the value of the patient's life.¹⁸²

173. DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 8, at 135 n.43.

174. *Id.* at 135 & n.44 citing *In re Guardianship of Roe*, 383 Mass. 415, 435, 421 N.E.2d 40, 58 (1981).

175. *Id.* at 135.

176. *Id.* at 134 (footnote omitted).

177. *Id.* at 136.

178. *Id.* (footnote omitted).

179. See *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 1022, 195 Cal. Rptr. 484, 491 (1983).

180. DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 8, at 135 n.43.

181. *Id.*

182. The Commission recognized the dangers for abuse inherent in a standard which relies on the legally useful, yet fictional, "average, reasonable person in the patient's position" when it asserted that "especially stringent standards of evidence should be required to support a claim that the average, reasonable person in the patient's position would disregard personal interests [for example, in prolonging life or avoiding suffering] in order to avoid creating emotional or financial burdens for their family or other people to whom they were close." *Id.* at 136 & n.45 (citing *Leach v. Akron General Medical Center*, 426 N.E.2d 809 (C.P. Summit County, Ohio 1980)). Precisely what the nature of these "especially stringent" evidentiary standards would be is an intriguing question which the Commission did not address.

The only "especially stringent" evidentiary standards currently in use are "clear and convincing evidence" and "evidence beyond a reasonable doubt". See generally MCCORMICK ON

In sum then, the New Jersey Supreme Court in *Conroy* accepted a limited functional definition of the rights of the human person when it "condon[ed] a restricted evaluation of the nature of a patient's life in terms of pain, suffering, and possible enjoyment," but it did recognize the risk in allowing "assessments of the personal worth or social utility of another's life, or the value of that life to others" to be the guide for third-party decision-making. By contrast, the President's Commission report explicitly advised that a functional definition be accepted when it urged that the views of "the average, reasonable person in the patient's position"¹⁸³ regarding "the emotional or financial burdens for their family or other people to whom they were close"¹⁸⁴ are to be given determinative weight if supported by credible evidence.¹⁸⁵

When considered together, *Conroy* and the decisions of federal and state courts resolving the same issues in the context of handicapped infants and children show a marked resemblance. In *American Academy of Pediatrics v. Heckler*¹⁸⁶ the guardians were held to have a right to demand an inquiry into "the quality of the infant's expected life"¹⁸⁷ and the potential for adverse "economic, emotional and marital effects on the family as a whole" due to "the effort to preserve an unwanted child."¹⁸⁸ In the original Indiana

EVIDENCE §§ 336-41 (E. Cleary 3d ed. 1984). How either of these standards can be brought to bear to determine the choice of an imaginary creature of legal fiction, the "average, reasonable person in the patient's position," is not stated. More likely, the decision will be a simple assumption of the sort which appears to have been made in the quotation from the Massachusetts Supreme Judicial Court which appears in footnote 44: "An individual who is part of a closely knit family would doubtless take into account the impact his acceptance or refusal of treatment would likely have on his family." DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 8, at 136 n.44 (quoting *In re Richard Roe II*, 421 N.E.2d 40, 58 (Mass. 1981)).

The contrast is notable. By rejecting the evidence before it concerning the incompetent's wishes as insufficient, the *Conroy* majority emphasized that more convincing and relevant proof than a mere recitation of the patient's deteriorating condition and assertions regarding his or her alleged distaste for medical treatment was required under any of the three tests it had just approved. See *Conroy*, 98 N.J. at 385-87, 486 A.2d at 1243-44. The reason, in its view, was obvious: "The consequences are most serious — life or death." *Id.* at 387, 486 A.2d at 1244. The Commission report, on the other hand, does not rely on either the patient's own assertions regarding treatment, or a stringent standard for determining what is in the patient's best interests by reference to the patient's interests alone. It applies the undefined "especially stringent standards" it recommends to the proof of what the "average, reasonable person in the patient's condition" would do. In this writer's judgment, there is a considerable difference between the two approaches. See *infra* notes 234-44 and accompanying text.

183. DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 8, at 136 & n.45.

184. *Id.*

185. *Id.*

186. 561 F. Supp. 395 (D.D.C. 1983).

187. *Id.* at 400.

188. *Id.*

"Baby Doe" case,¹⁸⁹ the decision to permit an infant with Down's Syndrome to die of dehydration and starvation was based on the parents' judgment that "Down's children never lead very good lives" and that "it would be wrong to subject [the child] to a life of such an inferior kind."¹⁹⁰ Like the decision in *American Academy of Pediatrics v. Heckler*,¹⁹¹ "[t]here were also [the parents'] other two children to consider, [because it was alleged] severely handicapped child would place a tremendous burden on the family as a whole."¹⁹²

An identical result was reached *In re Phillip B.*,¹⁹³ a 1979 California case involving parental refusal to permit a life-saving operation with minimal risk on a twelve year old boy afflicted with Down's Syndrome. The grounds: the father's belief that "he would be better off dead" and the alleged detrimental impact the child's condition had on his other two brothers.¹⁹⁴ Other cases could be cited at both ends of the biological continuum,¹⁹⁵ but the clear trend is in the direction of quality-of-life judgments of the sort approved in principle in the cases summarized above.

189. *In re Infant Doe*, No. GU 8204-00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *aff'd sub nom.*, State of Indiana on Relation of Infant Doe by Guardian, No. 482 S139 (Ind. S. Ct. May 27, 1982), No. 482 S140 (Ind. S. Ct. Apr. 26, 1983), *cert. denied*, 464 U.S. 961 (1983).

190. J. LYONS, PLAYING GOD IN THE NURSERY 32 (1985).

191. 561 F. Supp. 395 (D.D.C. 1983).

192. Lyons, *supra* note 190, at 32.

193. *In re Phillip B.*, A. Minor, no. 66103 (Super. Ct., Santa Clara County, Calif., Apr. 27, 1978), *aff'd*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980). After the Supreme Court denied *certiorari* in *Phillip B.* the Superior Court of Santa Clara County, California transferred guardianship of the person of Phillip Becker to the couple who sought to have the lifesaving surgery performed over the objections of Phillip's parents. Guardianship of Phillip Becker, No. 101981 (August 7, 1981). For a detailed discussion of the *Becker* case, see Destro & Moeller, *Necessary Care for the Retarded Child: The Case of Phillip Becker*, 4 HUM. LIFE REV. 81 (1980).

194. See Destro & Moeller, *supra* note 193, at 89 & n.41 (quoting Transcript of Record, *In re Phillip B.*, A. Minor, No. 66103 (Super. Ct., Santa Clara County, Cal. Apr. 27, 1978)).

195. See, e.g., *Maine Medical Center v. Houle*, No. 74-145 (Super. Ct. Cumberland, Me. filed Dec. 14, 1979); *In re Cicero*, 101 Misc. 2d 699, 421 N.Y.S.2d 965 (1979). In contrast with the cases resting on a quality-of-life ethic, the *Houle* court had little qualms about applying a natural rights ethic:

[A]t the moment of live birth there does exist a human being entitled to the fullest protection of the law. The most basic right enjoyed by every human being is the right to life itself. . . . The issue before the court is not the prospective quality of the life to be preserved, but the medical feasibility of the proposed treatment compared with the almost certain risk of death should treatment be withheld. Being satisfied that corrective surgery is medically necessary and medically feasible, the court finds that the defendants herein have no right to withhold such treatment and that to do so constitutes neglect in the legal sense.

Maine Medical Center v. Houle, No. 74-145 (Super. Court, Cumberland, Me. filed December 14, 1979), quoted in J. Robinson, *Legal Aspects of Withholding Medical Treatment from Handicapped Children*, in *INFANTICIDE AND THE HANDICAPPED NEWBORN* 24 (D. Horan & M. Delahoyde, eds. 1982)

The common thread in each of the cases is the functional ethic. Whether the quality-of-life rationale is stated explicitly, or hidden behind invocations of the talisman's of "privacy," "self-determination," or "medical judgment," the result is the same: the courts have accepted the initial premise of an ethic which will, in time, swallow the carefully crafted legal protection presently available to those who are afflicted with disabilities.¹⁹⁶ Judicial authorization of third-party judgments that rest on express statements to the effect that those with severe handicaps "never lead very good lives," that they are "better off dead," or that their right to equal treatment should depend on the "economic, emotional and marital effects on the[ir] family as a whole,"¹⁹⁷ is an open invitation to the making of legal policy which is based on precisely the "irrational prejudice against the mentally retarded" condemned in the Supreme Court's decision in the *Cleburne Living Center*¹⁹⁸ case discussed in Part I.

D. Rejecting the Functional Definition: A Legal Argument

In the Introduction to Part II it was noted that the distinction between "what is" and "what should be" in the law is often a fine one which tends to be overlooked when there is pressure for the court "to do what is right" under the circumstances. The cases summarized above in both the text and the footnotes demonstrate that this is especially true when the issues pending before a court involve difficult questions of biomedical ethics and public policy; the pressure to reach a humane result given the wrenching personal circumstances of the litigants is obvious from the language the courts employ.¹⁹⁹ Nonetheless, there can be no question that the duty of a court is to apply the law as written if it is applicable to the case at hand; for it is the

196. The California Supreme Court's recent decision invalidating the statutory protection against involuntary sterilization of the mentally incompetent, *Conservatorship of Valerie N.*, 40 Cal. 3d 143, 707 P.2d 760, 219 Cal. Rptr. 387 (1985), is another example of the way in which the functional ethic is given free reign once "privacy" and "self-determination" rationales are utilized to permit third-parties to exercise the alleged "rights" of the disabled on their behalf. Existing legal protection, in this case California's prohibition against eugenic sterilization, CAL. PROB. CODE § 2356(d) (West 1985); CAL. WELF. & INST. CODE § 4500 (West 1985), falls under the relentless logic of constitutional reasoning now bereft of its natural rights ethic. The only difference, in this writer's view, between cases such as *Conservatorship of Valerie N.* and *Buck v. Bell*, is their rationale. *Buck*, at least, took a direct approach without dressing it up in high-sounding statements of constitutional principle. At bottom, such "rights" are nothing more than legal fictions when applied to a person incapable of exercising the right. *Conservatorship of Valerie N.*, 40 Cal. 3d 143, 707 P.2d 760, 219 Cal. Rptr 387, 408-20 (1985) (Bird, C.J., dissenting).

197. *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 400 (D.D.C. 1983).

198. *Cleburne*, 105 S. Ct. at 3249.

199. See, e.g., *In re Conroy*, 98 N.J. 321, 364-65, 486 A.2d 1209, 1231 (1985) (quoted *supra* in text accompanying note 162).

legislatures, not the courts, which have the primary responsibility for the formulation of public policy.²⁰⁰

The difficulty arises when the law as written requires a result which the judges or the litigants perceive to be inhumane, burdensome, or otherwise inconsistent with what is considered to be an "appropriate" outcome given the circumstances. This was clearly the case in *American Academy of Pediatrics v. Heckler*,²⁰¹ *United States v. University Hospital*,²⁰² and *In re Conroy*.²⁰³ Each of the courts involved was cognizant that the law as written certainly did not authorize the actions they took, and in both *Heckler* and *University Hospital* they were aware that its plain language and legislative history could be construed to prohibit them.²⁰⁴ The means they employed to skirt existing law was a process of functional definition and avoidance.

In both *Heckler* and *University Hospital* the central legal question was the application of Section 504 of the Rehabilitation Act of 1973²⁰⁵ to cases alleging refusal to treat handicapped newborns because their handicaps give them a limited prognosis for a "normal" healthy childhood. Although the more technical legal issues of the Section 504 controversy involved in the cases are beyond the scope of this essay, the main issue — whether a handicapped infant is an "otherwise qualified individual" who is protected by the statute from discrimination in any federally funded program "solely by reason of his [or her] handicap" — is not.

As Part I points out, the primary issue in the application of Section 504 is whether or not a disabled person is able to reap the intended benefit of the program or service offered by the federal grantee.²⁰⁶ If so, the disabled persons must be offered at least the same level of benefits and services as are offered to those without disabilities.²⁰⁷ The question in the *Heckler* and *University Hospital* cases, and the question which is currently before the Supreme Court in *Heckler v. American Hospital Association*,²⁰⁸ is whether this rule applies to handicapped infants²⁰⁹ when those charged with their

200. Compare U.S. CONST. art. I, § 8, cl. 18 with, U.S. CONST. art. III.

201. 561 F. Supp. 395 (D.D.C. 1983).

202. 729 F.2d 144 (2d Cir. 1984).

203. 98 N.J. 321, 486 A.2d 1209 (1985), *rev'g*, 190 N.J. Super. 453, 464 A.2d 303 (1983) *rev'g*, 188 N.J. Super. 523, 457 A.2d 1232 (1983).

204. It is interesting to note that shortly after the decision by the courts to invalidate the regulations promulgated under Section 504, Congress adopted the Child Abuse Amendments of 1984, which prohibit, among other things, failure to provide appropriate treatment, food and water to disabled infants. 42 U.S.C. § 5102 (1982).

205. 29 U.S.C. § 794 (1982).

206. See *supra* text accompanying notes 44-52.

207. See *supra* text accompanying notes 53-68.

208. (unreported) (2d Cir. 1984), *cert. granted*, 105 S. Ct. 3475 (1985).

209. There is no question that such refusal to treat a child without a disability would con-

primary care decide to reject the services because the child is disabled.²¹⁰

The question is an important one, for it marks the first time the federal courts have applied an overtly functional ethic to constitutional protection under the Fifth and Fourteenth Amendments.²¹¹ Unlike *Roe v. Wade*,²¹² which created the right to abortion by limiting the class of "persons" entitled to legal protection of their lives to those members of the human species already born,²¹³ the cases involving newborns with disabilities are the first to permit eugenic, functional criteria to determine the degree of protection to those already born. As in *Roe*, the rationale employed is the alleged "privacy" of the parent-physician relationship, and the result is identical: denial of existing legal protection for lives which do not meet whatever quality-of-life criteria are employed by the parents or physicians. The significant point, however, is that the "privacy" rationale is designed to eliminate the protection of the subject individuals by insulating the illegal activity of others from legal scrutiny. By proceeding in this manner, the courts need never reach an

stitute child abuse (medical neglect) under the laws of every state. See sources cited *supra* note 114. The difficulty, of course, is that some courts charged with the responsibility of deciding medical neglect cases also apply a functional standard to judge the future quality of the child's life. In these cases, the parental refusal of care is deemed to be reasonable under the circumstances. See, e.g., *In re Phillip B.*, A. Minor, no. 66103 (Super. Ct., Santa Clara County, Calif., Apr. 27, 1978), *aff'd*, 92 Cal. App. 3d 796, 156 Cal. Rptr. 48 (1979), *cert. denied*, 445 U.S. 949 (1980).

210. Phrased in this manner, the issue is identical to other medical neglect proceedings where the parents refuse necessary medical treatment to their children. See sources cited *supra* notes 112, 114. One of the most common reasons why parents refuse such treatment—religious objection—is, in fact, constitutionally based and rests on a far firmer constitutional ground—the first amendment—than a vague and undefined "right to privacy." The difference in result, however, is striking. It is a rare case indeed when parents are permitted to refuse needed treatment to their children on religious grounds, notwithstanding the parents' express constitutional right to free exercise of religion. See *supra* note 114. Even in the face of express constitutional values which would seem to permit the parents wide latitude in choosing whether and how their child shall be treated, the courts have no difficulty in holding that their primary consideration must be the "best interests" of the child. It is *only* in cases where the child has a disability: that is, where the child is not considered by the court, the juvenile authorities, or the parents to have the potential for a "normal" childhood, that the usual rule requiring consideration of *only* the child's interests is transmogrified into a rule which looks to all the reasons why the child should *not* be treated or fed. See, e.g., *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 400 (D.D.C. 1983) (the potential for adverse "economic, emotional and marital effects on the family as a whole" due to "the effort to preserve an unwanted child"); *In re Phillip B.*, *supra* note 193 (impact on family); J. LYONS, *PLAYING GOD IN THE NURSERY* 32 (1985) (because "Down's children never lead very good lives" and "it would be wrong to subject [the child] to a life of such an inferior kind") (summarizing *In re Infant Doe*).

211. U.S. CONST. amends. V, XIV.

212. 410 U.S. 113 (1973).

213. *Id.* at 158.

overt discussion of the legitimacy of the functional, eugenic criteria used to justify the lack of equal treatment.

Under Section 504, the only legally relevant inquiry concerns the child's ability to reap the intended benefit from the treatment. If so, the next question is whether the treatment which is denied a handicapped "unwanted" infant would be provided for a "normal" or "wanted" infant suffering from the same or a similar condition requiring identical treatment. Analyzed in this manner, the issue in *American Hospital Association*²¹⁴ — whether or not the government is entitled to documents which will enable it to determine the criteria used by parents and physicians to deny treatment to infants with disabilities — goes to the heart of the entire controversy over the gradual adoption of a functional, eugenic ethic by American law. If hospitals receiving federal funds may bar inquiry by civil rights officials on grounds of family privacy, the privacy rationale will have successfully prevailed over the law's substantive requirements. If infants with disabilities are not "otherwise qualified individuals" entitled to equal treatment under Section 504 or state child neglect statutes because of their disabilities,²¹⁵ then the class of persons entitled to equal protection of the laws has been narrowed by the application of functional criteria.

The most obvious example of the application of the functional ethic to the disabled is the "food and water" issue. That is: can food and water be withdrawn with the intention of causing death by starvation or dehydration? The issue is a key one, for it is clearly at the cutting or transitional "edge" of current law.

From a legal perspective, the only question under Section 504 is whether or not the disabled patient can receive the intended benefit from continued feeding and hydration. The "common sense" approach to this question, of course, is to ask what benefit food and water provides to those without disabilities? The answer, quite simply, is that, along with shelter, food and water are among the most basic requirements of life.²¹⁶ No one can live without

214. In *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395, 400 (D.D.C. 1983) Judge Gesell used the term "unwanted child" — a term common to the debates over abortion — to describe a handicapped infant whose quality of life did not rise to the level desired by his or her parents. *Id.*

215. *United States v. University Hosp.*, 729 F.2d 144, 156-57 (2nd Cir. 1984). See generally *supra* note 149.

216. The debate has not yet reached the stage where it has been argued that death by exposure—the method preferred by the ancient Romans for disposing of unwanted infants and by some bands of the Inuit for the disabled elderly, see generally, L. EDELSTEIN, *ANCIENT MEDICINE: SELECTED PAPERS OF LUDWIG EDELSTEIN* 13 & n.21 (O & C.L. Temkin eds., C.L. Temkins trans. 1967); E. WEYERS, JR., *THE ESKIMOS: THEIR ENVIRONMENT AND FOLKWAYS*, 137-39 (1939), should be permissible, although there has been commentary to the effect that assisted suicide and active euthanasia should be permissible when the victim had no

them, and refusal to provide them with the intent of causing death raises far more substantial issues than simply overcoming the barriers caused by the "emotional significance" or "symbolism" of feeding noted by the California and New Jersey courts in *Barber* and *Conroy*.²¹⁷

As was pointed out in Part I, *Alexander v. Choate*²¹⁸ held that "[t]he balance struck [by Section 504] requires that an otherwise qualified handicapped individual must be provided with meaningful access to the benefit that the grantee offers."²¹⁹ This means that the disabled must be offered at least the same level of services as are offered to those without disabilities. Taken together with the holding in *Southeastern Community College v. Davis*²²⁰ that the handicapped individual must be able to reap the intended benefit of the service offered, there can be no doubt that provision of food and water in a manner which does not harm the patient — even if it does nothing more than sustain life — is required by Section 504. More importantly, the Supreme Court made it clear in *Choate* that "[t]he benefit itself, of course, cannot be defined in a way that effectively denie[s] otherwise qualified handicapped individuals the meaningful access to which they are entitled."²²¹

prognosis for a quality-of-life considered by the victim or others alleged to be acting in the victim's "best interests" to be acceptable. See, e.g., Levin & Arluke, *Getting Rid of Old People* Minn. Star and Tribune, Oct. 7, 1983, at 19A, col 3; Otten, *Can't We Put My Mother To Sleep?*, Wall St. J., June 5, 1985 at 133 col. 3. In this writer's judgment, the reasons that starvation and dehydration are currently being urged — notwithstanding their physical cruelty — is that they can be carried out under medical auspices which give an aura of respectability to actions which, if performed outside a hospital on a healthy person, would promptly be branded as murder. In addition, the fact that some forms of feeding and hydration do involve medical treatments of questionable value and risk to the patient gives credence to the argument that *all* feeding performed by medical personnel "in the realm of complex, high-technology medical care" is "medical treatment." This appears to have been the position adopted by the New Jersey Supreme Court in *Conroy*, and it was recently adopted by the American Medical Association's Council on Ethical and Judicial Affairs. See *In re Conroy*, 98 N.J. at 372-74, 486 A.2d at 1235-37 and sources cited therein. See generally E. HEALY, *MEDICAL ETHICS* (1956); Lo & Dornbrand, *Sounding Board: Guiding the Hand that Feeds: Caring for the Demented Elderly*, 311 NEW ENG. J. MED. 402 (1984); Lynn & Childress, *Must Patients Always Be Given Food and Water?*, 13 *Hastings Center Rep.* 17 (1983); Paris & Fletcher, *Infant Doe Regulations and the Absolute Requirement to Use Nourishment and Fluids for the Dying Infant*, 11 L. MED. & HEALTH CARE 210 (1983); J. PICCONE, *LAST RIGHTS: TREATMENT AND CARE ISSUES IN MEDICAL ETHICS* (1984); Zerwekh, *The Dehydration Question*, 13 *NURSING* 83 (1983). See also Rust, *Feeding Withdrawal Gets Conditional Nod*, Am. Med. News, Mar. 28, 1986, at 1, col. 1.

217. *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 1016, 195 Cal. Rptr. 484, 490 (1983); *In re Conroy*, 98 N.J. 321, 372, 486 A.2d 1209, 1236 (1985).

218. 105 S. Ct. 712 (1985).

219. *Id.* at 721.

220. 442 U.S. 397 (1979).

221. *Alexander v. Choate*, 105 S. Ct. at 721.

Thus, the "food and water" issue must be seen for what it is: the entering wedge of an ethic which would permit intentional steps to end the lives of the disabled. Because the functional ethic would permit such action only when the individual is disabled, the threat to existing law protecting the disabled is clear. Once intentional steps to cause death — rather than passive measures which permit the condition or disease to take its natural course — have been approved, the inescapable conclusion is that it is the *existence* of the disabled person which constitutes the undesirable condition.

The "remedy" for certain disabilities under the functional ethic is death. Food and water — the basic requirements of life itself — are redefined as medical "treatments" which can be withdrawn when the patient can no longer be made whole. Death, then, becomes the "final solution" for those whose disabilities make them — to borrow a phrase — "useless eaters".

If there were any doubt regarding the direction of the cases in which the new ethic is being urged on the courts, one need only examine the facts in *Brophy* and the recently-filed New Jersey case, *In re Jobes*.²²² In neither case is it seriously alleged that artificial feeding causes harm to the patient beyond maintaining their existence in a "vegetative" state. The real claim in these cases is that the disabled must be able to gain a greater benefit from food and water — relief from the disability itself — than those whose prognoses are good.

Death by starvation and dehydration is the common thread which runs through New Jersey's *Conroy* and *Jobes*, Massachusetts' *Brophy v. New England Sinai Hospital*,²²³ California's *Barber v. Superior Court*,²²⁴ and the original Indiana "Baby Doe" case.²²⁵ Each of the individuals involved were

222. *In re Jobes*, No. C-4971-85E (Super. Ct., Ch. Div., Morris City, N.J.) (pending). The case involves a 30-year-old woman whose condition is not comatose, and who is able to respond in a limited manner to verbal commands to move her toes, and who will follow movement in her room with her eyes. She is not in imminent danger of death, but her prognosis for recovery is not good. See *Nursing Home Opposes Removal of Comatose Woman's Life Support*, *The Star-Ledger*, Newark, New Jersey, Oct. 17, 1985, at A43, col. —; Press Advisory Regarding The Matter of Nancy Ellen Jobes, 10-17-85, by owners of Lincoln Park Nursing & Convalescent Home, Jeryl Turco, Licensed Nursing Home Administrator and Carla Turco Scolari, Licensed Nursing Home Administrator (opposing the removal of the feeding tube by court order because patient is not terminally ill, the provision of nutrients and water for this patient is not extraordinary care and the removal would jeopardize "[l]ong standing medical and nursing principles and sentiments, i.e., is to heal, comfort and sustain life, through common medical procedures and care . . .").

223. *Brophy*, *Guardian v. New England Sinai Hosp.*, No. 85E009-G1 (Mass. P. & Fam. Ct. filed Oct. 21, 1985).

224. *Barber v. Superior Court*, 147 Cal. App. 3d 1006, 195, Cal. Rptr. 484, (1983).

225. *In re Infant Doe*, No. GU8204-00 (Cir. Ct. Monroe County, Ind. Apr. 12, 1982), *aff'd sub nom.*, *State of Indiana on Relation of Infant Doe by Guardian*, No. 482, 5139 (Ind. S. Ct. May 27, 1982), No. 482, 5140 (Ind. S. Ct. Apr. 26, 1983), *cert. denied*, 464 U.S. 961 (1983).

suffering from disabling conditions, and in all the cases there was little, if anything, which could be done to correct their respective "defects." Clarence Herbert²²⁶ was in a stupor caused by brain damage. Conroy was severely impaired by chronic brain syndrome and Brophy suffered severe midbrain damage which blocked his capacity to respond to most stimuli. Both were described as being in "persistent vegetative states".²²⁷ Jobses is severely brain-damaged and functionally impaired.²²⁸ Baby Doe was a Down's Syndrome child (mental retardation). Food and water would not cure them, but it would sustain their existence. The key is the disability — from Quinlan's and Herbert's total disability; to Infant Doe's mental retardation. Their life had lost its "value" to others. For each, the prescription of the functional ethic is the same: death by neglect, dehydration and starvation²²⁹ because the person was incurably disabled. In the eyes of those charged with the duty to protect and care for them they were no longer persons "in the whole sense."

The conclusion is now inescapable that the severely disabled have been singled out for lesser protection than the law would provide to "normal" patients with a good prognosis for recovery.²³⁰ In *Brophy* the trial court

Although the primary issue in this case was the provision of basic surgery to correct an intestinal blockage which made feeding by mouth impossible, the intended result of this action was to cause death by withholding oral or intravenous food and water. There can be no question that had the child been born without Down's Syndrome and with an intestinal blockage, the surgery would have been performed. See *supra* note 114.

226. *Barber v. Superior Court*, *supra* note 224, involved an attempted prosecution of two physicians, Barber and Nejd, for the death of one Clarence Herbert due to withdrawal of food and water.

227. As found by the court in *Brophy*, "a persistent vegetative state" is "a condition in which the patient:

- (a) shows no evidence of verbal or non-verbal communication;
- (b) demonstrates no purposeful movement or motor ability;
- (c) is unable to interact purposely with sti[m]ulation provided by his environment;
- (d) is unable to provide for his own basic needs;
- (e) demonstrates all of the above for longer than three months.

Brophy, *Guardian v. New England Sinai Hospital*, No. 85E009-G1, slip op. at 10 (Mass. P. & Fam. Ct. Oct. 21, 1985) (finding of fact #29).

228. Letter to Richard Traynor, Esq. from Maurice Victor, M.D., Director, Department of Neurology, Cleveland Metropolitan General Hospital (December 12, 1985) (discussing diagnosis) (available in author's file). See also *supra* note 222.

229. In *Brophy*, the court noted that "Brophy's attending physician was unable to imagine a more cruel and violent death than [sic] thirsting to death." *Brophy*, slip op. at 29 (finding #109).

230. The recent Florida murder case of Roswell Gilbert, convicted of murder for shooting his 73 year-old wife because she was suffering from Alzheimer's disease, is only one recent example of the gradual breakdown of the natural rights ethic. *State v. Gilbert*, No. 85-2596 CF. (Broward County, Fla., May 9, 1985) (jury verdict), *appeal pending*, No. 85-1129 (4th Dist. Ct. App.). See also Lane, *The Legal Year in Pictures*, 71 A.B.A.J., Dec., 1985, at 63.

found that "approximately 42% of the patients at the hospital were unable to feed themselves and required some form of artificial feeding,"²³¹ and that "[a] person who was otherwise healthy, would be quite capable of leading a normal, active lifestyle, which would include employment" with the type of feeding involved in that case (a gastrotomy tube).²³² Entitlement to equal protection of the law appears to turn on whether the individual is "otherwise healthy," rather than on his or her status as a "person " under the law. The protection afforded life and equality by the specific language of the Constitution itself has been changed in a fundamental way, without public debate, without legal formalities,²³³ and, most of all, without a clear understanding that the natural rights of every citizen have been diluted by judges who are sworn to uphold them.

III. ETHICAL CLARITY AND THE RULE OF LAW

From the perspective of law, terminology is important. In the words of the President's Commission "[l]aw is one of the basic means through which a society translates its values into policies and applies them to human conduct."²³⁴ Because words used in laws and judicial opinions have specific meanings, and the legal policy contained in that body of law has a substantial impact on the individuals and society which it governs, the public is entitled to clear notice of what meaning policymakers attach to the words they use. And when, as here, differences of opinion concerning the values of society which define the meaning of laws protecting the disabled and elderly may adversely affect constitutionally protected rights, the need for clarity is critical.²³⁵ Ambiguous legal terminology permits those having the power to enforce the law virtually limitless discretion to act in accordance with their

231. *Brophy, slip op. at 15.*

232. *Id.* (finding of fact #55).

233. See U.S. CONST. art. I, § V.

234. DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT *supra* note 8, at 30. Kelsen saw law as a "coercive order of human behavior" and that "the norms of the legal order regulate [it]." H. Kelsen, *PURE THEORY OF LAW* 31 (M. Knight trans. 1967):

"The first characteristic, then, common to all social orders designated by the word 'law' is that they are orders of human behavior. A second characteristic is that they are coercive orders. This means that they react against certain events, regarded as undesirable [sic] because detrimental to society, especially against human behavior of this kind, with a coercive act; that is to say by inflicting on the responsible individual an evil — such as deprivation of life, health, liberty or economic values — which, if necessary, is imposed upon the affected individual even against his will by the employment of physical force."

Id. at 33.

235. For a general discussion of the constitutional doctrines of vagueness and overbreadth in the context of freedom of speech, see W. LOCKHART, Y. KAMISAR & J. CHOPER, *CONSTITUTIONAL LAW* 730-38 (5th ed. 1980).

own personal predilections, bounded only by their own ad hoc determinations respecting their own authority.²³⁶ When the law is ambiguous, who but a superior authority is to say that those with enforcement authority are wrong? As Judge Ralph Winter has noted in dissent in *United States v. University Hospital*:²³⁷

Ambiguity pervades the majority opinion as to exactly which services and which handicapped persons are excluded from the statute. All one can know for certain is that some medical services may be denied to some handicapped persons, without running afoul of Section 504. The majority even implies, *inter alia*, that Section 504 may not apply at all to the provision of medical services . . . in the face of the explicit statement of the Senate Report that it "was enacted to prevent discrimination against all handicapped individuals . . . in . . . health services." . . . [T]he majority opinion also implies that . . . only certain kinds of handicapped persons are excluded. If that interpretation stands, then the federal courts may be forced to resolve individually each of these human tragedies and moral dilemmas.²³⁸

Although federal and state courts are quick to recognize and condemn such ambiguity in the policy pronouncements of legislative and executive bodies, the jurists writing majority opinions seem unable or unwilling to judge their own pronouncements by the same standard. The problem of unfettered judicial discretion is all the more serious when one considers that the judiciary is the only branch which lays claim to an indefeasible right to interpret the basic law in a manner which is binding on all others and reversible only by change of opinion or constitutional amendment. "We live under the Constitution, but the Constitution is what the judges say it is," said the late Chief Justice Charles Evans Hughes in 1907.²³⁹

But Hughes was wrong about the Constitution, even though the judges often succeed in their attempts to avoid the political processes which are the centerpiece of representative democracy. He was wrong because his comments both beg the question, and miss the point.

As applied to the issues discussed in this essay, it should be clear that judges have no authority, and even less (if that is possible) claim of expertise to undertake the task of redefining the fundamental ethic on which the con-

236. Constitutional law recognizes this principle when courts accept a "limiting construction" on an otherwise vague or ambiguous legal term. *Compare Cox v. New Hampshire*, 312 U.S. 569 (1941) with *Walker v. Birmingham*, 388 U.S. 307 (1967).

237. 729 F.2d 144, 161 (2d Cir. 1984) (Winter, J., dissenting).

238. *Id.* at 162-63 (citation omitted) (quoting S. REP. NO. 1297, 93d Cong., 2d Sess., reprinted in 1974 U.S. CODE CONG. & AD. NEWS 6373, 6388).

239. See *supra* note 79.

stitutional protection of human individuals is based. Their reliance on ethical "experts" who appear as witnesses or *amici curiae* does not supply what is missing either; for neither the judges, nor the self-appointed ethical "experts" are constitutionally adequate substitutes for the elected representatives of the people themselves. As a legal matter, the opinion of a judge or ethical "expert" that the "natural rights" ethic of the Constitution or Section 504 of the Rehabilitation Act of 1973 is outmoded as applied to disabled infants is simply that — an opinion: interesting, but legally irrelevant.²⁴⁰ As a practical matter, however, the opinion of the judge that the court has the discretion to rewrite the ethic by indirection, is a serious matter indeed. For when that discretion is guided by an ethic as foreign to basic human rights principles as the functional ethic is to the natural rights theory on which American constitutional law is based, the law and the society which it governs will undergo a revolution in its basic approach to human rights questions.²⁴¹ Outcome, not principle, will be the goal, and inequality and discrimination will be the outcome.²⁴² There will be no need to fret about

240. See *supra* note 92.

241. Once again, it seems appropriate to note that most of the countervailing interests mentioned in the President's Commission report — self-determination, well-being, and equity — have little if anything to do with cases involving disabled newborns or severely disabled adults. When there is no clear evidence respecting the individual's "self-determination," candor compels the conclusion that it is a non-issue. Similarly, "well-being" is a perfectly legitimate criterion assuming that the medical intervention contemplated will result in harm, but it is stretching the concept to its breaking point to assert that death is in a patient's best interests whenever the intervention will do nothing more than palliate or maintain. Equity is the most problematic, for it seeks to balance the value of the patient's life against the interests of others or the desires of the hypothetical "reasonable person in the patient's condition" when faced with questions of resource allocation. See *supra* notes 174-82 and accompanying text.

242. As pointed out in the introduction to this essay, the debate over the right of the disabled and handicapped to equal treatment by the law has significant parallels in the areas of affirmative action and separation of church and state. Because the Supreme Court has yet to define whether "separation" or "religious freedom" is the core principle of the Establishment Clause of the first amendment, it has mandated discrimination in the distribution of public benefits in the face of legislative determination to provide equal treatment for individuals who exercise their right to choose not to attend state schools. *Pierce v. Society of Sisters*, 268 U.S. 510 (1925). See *Aguilar v. Felton*, 105 S. Ct. 3232 (1985); *Grand Rapids School District v. Ball*, 105 S. Ct. 3216 (1985) (Neither Congress nor the State of Michigan could constitutionally require or permit the provision of on-site remedial or enrichment educational services identical to those offered children in the public schools to children whose parents exercised their constitutional right to choose a religious education because of the appearance of a "symbolic union of government and religion," even though "no evidence of specific incidents of religious indoctrination" had been proved.). Similarly, the lower courts have approved affirmative action programs which, although explicitly stating a racial or ethnic preference, further a result consistent with a social welfare conception of "equality", largely because the Supreme Court has yet to come to grips with the meaning of the Equal Protection Clause of the fourteenth amendment. See, e.g., *Firefighters Local Union No. 1784 v. Stotts*, 467 U.S. 561 (1984); *Fullilove v. Klutznick*, 448 U.S. 448, 533-40 (1980) (Stevens, J., dissenting); *Regents of the*

"slippery slopes"; the slope itself will be levelled.²⁴³

This is precisely the difficulty with recent judicial pronouncements cutting back on the protection afforded certain classes of disabled infants and adults. Words which do have a clear legal meaning (i.e., "no person shall be deprived of life," "food and water") have either been avoided altogether, or rendered ambiguous by judicial acceptance of a result-oriented, functional human rights ethic (*viz*: calling hydration "treatment" in order to avoid the implications of accuracy). And those which have no fixed meaning (i.e. "treatment," "death") now mean whatever the court considers to be consistent with the adoption of the new ethic.²⁴⁴

Univ. of Cal. v. Bakke, 438 U.S. 265 (1978); Wygant v. Jackson Bd. of Ed., 546 F. Supp. 1195 (E.D. Mich. 1982), *aff'd*, 746 F.2d 1152, 1156 (6th Cir. 1984), *cert. granted*, 105 S. Ct. 2015. An interesting perspective on this issue as it relates to equality is presented in Howard & Howard, *The Dilemma of the Voting Rights Act — Recognizing the Emerging Political Equality Norm*, 83 COLUM. L. REV. 1615 (1983), in which the authors point out that the creation of "safe" voting districts for minorities alleged to be required by the fourteenth amendment and the Voting Rights Act may conflict with what they describe as the "political equality norm," which would restrict legislative or judicial ability to gerrymander for political or social purposes. The key, of course, is to arrive at a principled definition of key terms. If unacceptable results are achieved, the political process is available to adjust them. See generally Destro, *Equality, Social Welfare and Equal Protection*, 9 HARV. J. LAW & PUB. POL'Y 51 (1986).

243. The President's Commission found that the cost of accepting "slippery slope" arguments might be "the continued prohibition of some conduct which is actually acceptable." DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT *supra* note 8, at 28-30. While this statement is true insofar as it affects activities which may be acceptable, the point made in the text is to emphasize that without a clear anchor in first principle, the law can rapidly progress to the point where unacceptable behavior is sanctioned. It is the ethic which governs the policymakers, not their propensity to excess, which must be the subject of judicial and public scrutiny. Once the ethic itself undergoes revision, it is pointless to speak of "slippery slopes"; the concept presumes slippage from an identifiable point of principle. If that point is changed, the contours of the slope itself change with it. The President's Commission implicitly recognized this point, but did not discuss its importance, when it quoted the following language from Sisela Bok's *Death & Dying: Euthanasia and Sustaining Life: Ethical Views*, in 1 ENCYCLOPEDIA OF BIOETHICS 268, 277 (1978):

We do not always possess clear natural lines. Such a realization is sometimes thought to imply that all distinctions are useless, so long as they are not mirrored in nature. But it is crucial to see that, even though a line is not drawn in nature, it may well be needed in practice. . . . All social policy requires the drawing of lines. . . . Prohibitions have to be established and distinctions made even where human affairs are uncertain and hard to classify.

DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 8, at 29-30 n. 52.

One need only look at the development of the case law and recent news reports concerning the incidence of alleged "mercy killings," including one in California in which several nurses were held at gunpoint and forced by the son of a cancer patient to "pull the plug" on his father's life support systems, to see that the public is beginning to sense that the ethic governing the permissibility of active measures has weakened. *Arraignment in Gunpoint Mercy Killing*, United Press International, Dec. 24, 1985 (available on NEXIS, NEXIS library, wires file). See also sources cited *supra* notes 216, 222-30.

244. In *Conroy*, 98 N.J. 321, 486 A.2d 1209 (1984), the court, in its zeal to bring the

Thus, the central issue in cases such as Indiana's Baby Doe, *Jobes*, *Conroy*, *Barber*, and *Brophy* is not "treatment" at all, but whether the law will permit the intentional termination of the lives of disabled persons because there is no current way to improve their disabling conditions. The law has now reached a "point of no return": a point where policymakers and judges have a legal and moral obligation to recognize frankly that it is not the disease or disability which kills the patient, but an act of omission done with the specific intent of bringing about the death of a disabled individual.²⁴⁵ Once this point is passed, the distinction between acts of commission and omission, when both are intended to kill, becomes more apparent than real.²⁴⁶

For the law to afford less protection to the lives of the disabled because of

decisional law of New Jersey up-to-date with the most recent medical thinking, obliterated most of the distinctions which have been useful in highlighting the issues in the debate over euthanasia of the terminally ill. Food and water become "treatments" because there is no point to maintaining the "emotional significance" of feeding in such a complex medical environment; an educated medical opinion that the person will die within six months becomes the functional equivalent of imminent death; and "active" and "passive" measures become indistinguishable for legal purposes. *Id.* at 369-74, 486 A.2d at 1233-37. There is not much of a "slope" left to slide down after all this. Similarly, in the late 1970's much of the debate centered over the acceptability of the Harvard "brain death" criteria. Not so today. The issue before the courts in cases such as *Conroy* and *Brophy* is not whether the afflicted individual is dead — they are not — the issue is whether they *should* be dead, and what steps can be taken to hasten the process. But this is not how the issue is framed for the court; the approach is more indirect. The incompetent person is said to be "vegetative": "functionally" dead, a "vegetable," not a person. The infant with disabilities is similarly depersonalized, and serious commentators and judges debate whether a law which refers to "handicapped persons" even applies to such a child. See *supra* notes 145-49 and accompanying text. The disabled child is now a "defective" newborn, and the quality of its life is evaluated by a formula: $QL = NE \times (H + S)$ where QL = Quality of Life; NE = Natural Endowment, both physical and intellectual; H = the contribution of home and family; and S = the contribution from society. Shaw, *Defining the Quality of Life*, 7 HASTINGS CTR. REP. 11 (1977); Gross, Cox, Tatyrek, Pollay & Barnes, *Early Treatment and Decision Making for the Treatment of Myelomeningocele*, 72 PEDIATRICS 450 (1983).

245. The California case noted *supra* note 243 involving a son forcing nursing personnel, at gunpoint, to terminate his father's life support systems after surgery, and the coroner's subsequent ruling that the father died — not as a result of the son's actions, but from the disease which brought him to the hospital (cancer) — is a pristine example of the manner in which the law avoids facing the difficult questions. While this writer would not presume to question the coroner or prosecutor's motives for deciding as they did, there is no question that there is an implicit message in the decision not to file an information for murder. Whether the prosecuting authorities were sympathetic with the son's (or the father's) plight, or feared that a jury might be, will never be known.

246. The recent Florida murder case of Roswell Gilbert, a man convicted of murder for shooting his 73 year-old wife because she was suffering from Alzheimer's disease, is a good example of this trend. See *supra* note 230. Mr. Gilbert argued after his conviction that he should be pardoned because the killing was justifiable as an act of "mercy killing." See Lane, *The Legal Year in Pictures* 71 A.B.A.J., Dec. 1985, at 63. The argument was rejected by a majority of the Florida governor's cabinet. *Id.*

their disability raises profound questions under the Equal Protection Clause of the fourteenth amendment because it reflects the age-old prejudice against the mentally retarded and disabled condemned in the Supreme Court's decision in *Cleburne Living Center*.²⁴⁷ Worse, it entangles the law in the profound ethical and moral question of whether the ultimate aim of medical treatment is always to cure or rehabilitate,²⁴⁸ without the benefit of full and open debate over the social implications of such a policy in the only forum designed for such debate — the legislature.

Thus, it is time to admit frankly that the law has now regressed, by increments, to the stage where it is now arguably legitimate to authorize active steps which are intended to end a person's life because he or she is disabled.²⁴⁹ That such activity is prohibited under existing statutory and con-

247. *City of Cleburne, Texas v. Cleburne Living Center, Inc.*, 105 S. Ct. 3249, 3262, 3266-72(1985) (Marshall, Brennan & Blackmun, JJ., concurring in part and dissenting in part) (Stevens, J., & Burger, CJ., concurring).

248. In 1949, Leo Alexander, an observer at the trials of the Nazi war criminals at Nuremberg wrote that it was the shift in ethic within the medical profession which allowed the terror to begin; the law simply took advantage of an already fertile climate of eugenic opinion and developed it far beyond the point most would consider civilized:

The original concept of medicine and nursing was not based on any rational or feasible likelihood that they could actually cure and restore but rather on an essentially maternal or religious idea. The Good Samaritan had no thought of nor did he actually care whether he could restore working capacity. He was merely motivated by the compassion in alleviating suffering. Bernal states that prior to the advent of scientific medicine, the physician's main function was to give hope to the patient and to relieve his relatives of responsibility.

The beginnings at first were merely a subtle shift in emphasis in the basic attitude of the physicians. It started with the acceptance of the attitude, basic in the euthanasia movement, that there is such a thing as life not worthy to be lived. This attitude in its early stages concerned itself merely with the severely and chronically sick. Gradually the sphere of those to be included in this category was enlarged to encompass the socially unproductive, the ideologically unwanted, the racially unwanted and finally all non-Germans. But it is important to realize that the infinitely small wedged-in lever from which this entire trend of mind received its impetus was the attitude toward the nonrehabilitable sick.

It is, therefore, this subtle shift in attitude that one must thoroughly investigate. Alexander, *Medical Science Under Dictatorship*, 241 NEW ENG. J. MED. 39, 41 & n.17 (1949) (quoting J. BERNAL, *THE SOCIAL FUNCTION OF SCIENCE* 44 (6th ed. 1946)). See also sources cited *supra* note 73.

249. Although few would argue overtly that the physician's only role is to heal, the law of medical malpractice has come very close to making the physician a guarantor of positive results. Obstetricians and gynecologists are now charged by the law of many states with the duty to warn parents that their unborn offspring are likely to be disabled, so that abortion will afford them the opportunity to "prevent" the problems associated with having a child with an incurable disability by eliminating the child through an eugenic abortion. It is the very *existence* of a child with a disability which has become the actionable harm, and the physician is expected to take steps to "prevent" the damage, whether before birth through abortion, or

stitutional law is a proposition so obvious that it would be a waste of time to argue it. The real issue is whether that law should be changed, and, if so, by whom and on what grounds?

The prejudice against the disabled and those with mental disabilities is a strong one, with a long and sordid history.²⁵⁰ If the courts are to counte-

afterwards by denial of appropriate treatment, or food and water. In either case, the reasoning is the same: the life of a child with severe disabilities is not worth living.

The same reasoning appears to be creeping into the thinking of courts dealing with the disabled at later and terminal stages of life. The "elderly, incompetent nursing-home resident with severe and permanent mental and physical impairments and a life-expectancy of approximately one year or less," *In re Conroy*, 98 N.J. 321, 363, 486 A.2d 1209, 1231 (1984), may now be dealt with in the same manner as the disabled infant — death by starvation and dehydration — if life-sustaining treatment does not offer the hope of a return to a "normal, integrated, functioning, cognitive existence." *In re Dinnerstein*, 6 Mass. App. Ct. 466, 380 N.E.2d 134, 138 (1978) (elderly, half-paralyzed victim of Alzheimer's disease). See also DECIDING TO FOREGO LIFE-SUSTAINING TREATMENT, *supra* note 8, at 135 (arguing for an objective "best interests" standard which will "take into account such factors as the . . . preservation or restoration of functioning, and the quality as well as the extent of life sustained"). But cf. *In re Conroy*, 98 N.J. at 367, 486 A.2d at 1232-33 (comparing its approach to those cited above). In keeping with this trend, the recent *Jobes* case in New Jersey seeks to extend the *Conroy* approach to include a 30 year-old female nursing home patient who is neither brain-dead, comatose, nor terminal within the one-year time period. See *supra* note 222 and accompanying text.

The "wrongful birth" cases cited *supra* impose a duty on the physician to warn, and hence, to test for potential genetic defects. See, e.g., *Robak v. United States*, 658 F.2d 471 (7th Cir. 1981) (Alabama law); *Turpin v. Sortini*, 31 Cal. 3d 220, 182 Cal. Rptr. 337, 643 P.2d 954 (1982); *Fassoulas v. Ramey*, 450 So. 2d 822 (Fla. 1984); *Blake v. Cruz*, 108 Idaho 253, 698 P.2d 315 (1984); *Berman v. Allan*, 80 N.J. 421, 404 A.2d 8 (1979); *Speck v. Finegold*, 497 Pa. 76, 439 A.2d 110 (1981); *Dumer v. St. Michael's Hosp.*, 69 Wis. 2d 766, 233 N.W.2d 372 (1975). When states have mandated the disclosure of information concerning the physical characteristics of normal fetuses, however, the courts have ruled uniformly that such information interferes with the right to choose abortion recognized by *Roe v. Wade*, 410 U.S. 113 (1973), because it is designed to prejudice the choice in favor of childbirth. See, e.g., *City of Akron v. Akron Center for Reproductive Health*, 462 U.S. 416, 442-49 (1983); *Thornburgh v. American College of Obstetricians and Gynecologists*, 737 F.2d 283 (3d Cir. 1984), *juris. postponed*, 105 S. Ct. 2015 (1985). From these cases, it is reasonable to assume that the courts have concluded that prenatal physiological characteristics are not relevant to the choice of a woman to have the child *unless the child is disabled*. Then, and only then, do the courts permit detailed physiological information concerning fetal characteristics to be disclosed. See *Blake v. Cruz*, 108 Idaho at 244, 698 P.2d at 318-22 (1984) (noting that although several courts have rejected claims based on the birth of normal, healthy children, "no court has rejected claims involving children with birth defects" because "society has a vested interest in reducing and preventing birth defects"). Accord *Fassoulas v. Ramey*, 450 So. 2d 822 (Fla. 1984) (cost of raising a normal child unavailable as damages, but excess cost of raising a disabled child is recoverable).

250. See, e.g., *Buck v. Bell*, 274 U.S. 200, 207 (1927) (approving sterilization of the mentally retarded confined to state institutions because, among other things, "three generations of imbeciles are enough"). Peter Singer is equally direct in his view of the severely retarded infant:

Once the religious mumbo-jumbo surrounding the term "human" has been stripped away, we may continue to see normal members of our species as possessing greater

nance that prejudice by permitting guardians to starve their wards, they should do so directly rather than mask them in high-sounding arguments claiming to rely on "privacy" and "self-determination." In cases where the patient is incompetent, the only "privacy" and "determination" being served is that of the guardian, not the ward. As Richard McCormick, S.J., has pointed out, such arguments both "beg the question and miss the point."²⁵¹ And they do so for a purpose: to hide the fact that the law is being changed through judicial acceptance of an ethic which prefers to redefine the law's

capacities of rationality, self-consciousness, communication, and so on, than members of other species; but we will not regard as sacrosanct the life of each and every member of our species, no matter how limited its capacity for intelligent or even conscious life may be. If we compare a severely defective human infant with a non-human animal like a dog or a pig, for example, we will often find the nonhuman to have superior capacities, both actual and potential, for rationality, self-consciousness, communication, and anything else that can plausibly be considered morally significant. Only the fact that the defective infant is a member of the species *Homo Sapiens* leads it to be treated differently from the dog or pig. Species membership alone, however, is not morally relevant.

* * *

If we can put aside the obsolete and erroneous notion of the sanctity of all human life, we may start to look at human life as it really is: at the quality of life that each human being has or can achieve. Then it will be possible to approach these difficult questions of life and death with the ethical sensitivity that each case demands, rather than with . . . blindness to individual differences. . . .

The difficulty with this rationale, however, is that it has no stopping point. The "sensitivity that each case demands" is a focus on the precise individual differences which have been the basis for discrimination against the disabled and mentally retarded. Certain courts have already adopted the functional ethic, and it is quite clear that they are not stopping with those who are in "vegetative" states: Phillip Becker was a otherwise healthy twelve-year old with Down's Syndrome who would die without surgery to correct a heart wall defect; Infant Doe was an otherwise healthy infant with another condition related to Down's Syndrome, duodenal atresia, and Nancy Jobes is a 30 year-old woman who is non-comatose, but considered by her family to be "vegetative". The law simply expands, and ethicists argue for "sensitivity . . . to individual differences" which will only expand it further. See also *Conservatorship of Valerie N.*, 40 Cal. 3d 143, 219 Cal. Rptr. 387, 707 P.2d 760 (1985). See generally Hentoff, *The Awful Privacy of Baby Doe*, THE ATLANTIC MONTHLY, Jan. 1985, at 54-62.

251. Once again, it is useful to note Richard A. McCormick's argument that [m]ost of the analyses that deserve the title "poor" or "invalid" fit into either of two categories *petitio principii* (begging the question), or *ignorantia elenchi* (missing the point). *Moral Argument and Christian Ethics*, *supra* note 86, at 13. In this context, bad legal arguments are, in this writer's opinion, those which rely on the opinions of ethical experts to argue for judicial change in existing law without reference to established policy protecting the disabled. Were the ethical opinions put forth in such cases so universally accepted as to be legitimate grounds for judicial decisions, there would be little doubt that the law would change in its normal way: through enactment and repeal of new statutory norms. Thus, all the judicial and ethical question-begging does indeed have a point: to change the law without regard to the sometimes messy and unpredictable legislative and political processes prescribed by state and federal constitutions.

essential terms, rather than to state explicitly its goals and their implications for those with disabilities.

CONCLUSION

In sum, the law is in the process of adopting a functional definition of the value of the human person, but it is doing so by indirection. If the law cannot countenance a direct statement that the severely disabled are, in the words of one guardian who refused treatment for his son, "better off dead," then it should act accordingly and refuse to permit guardians to starve their wards. That there are profound questions of medical ethics and morality involved in this debate is not open to serious question, but the ethical and moral debate must not be confused with the requirements of the law as it now stands. Whether the law should be legislatively infused with a new ethic is another question, for another essay. But my remarks to this point leave very little doubt that I do not believe that courts should fill the vacuum created by legislative inaction by simply resolving cases in favor of the death of the ward. The principles involved are far too important, and *ad hoc* decision-making in emotional cases is making bad law. Though it may take some time, I do believe that we will live to regret leaving to lawyers, doctors, judges, legislators and ethicists the important task of deciding who among the disabled shall live, and who shall die. We have been down that road before.